**ORIGINAL PAPER** 



# Socio-religious Prognosticators of Psychosocial Burden of Beta Thalassemia Major

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# Abstract

The study investigates the socio-religious factors in the propagation of genetically inherited disease of Beta thalassemia. The disorder which reportedly has a significant protraction through repeated cousin marriages results in the social maladjustment of the parents of the sick children due to constant depression, anxiety, and weak social interaction and may lead to social isolation as well. This research aims to find out the significant effect of socio-religious trends on psychosocial burden of beta thalassemia major among cousin and non-cousin couples in the province of Punjab in Pakistan. It takes a sample of 932 parents of sick children, among whom 735 were married with cousins and 197 with non-cousins, for data collection. The findings reveal that inadequate knowledge of the disease, insufficient or misdirected social support, stigmatization, and marriage breakups caused by the disease, superstitions, and misinterpretations of religion and the subsequent practices accordingly as significant predictors of psychosocial burden of beta thalassemia major among non-cousins and cousin couples. Additionally, it also finds patriarchy as only significant predictors of outcome variable among cousin couples.

Keywords Social  $\cdot$  Religious  $\cdot$  Psychosocial burden  $\cdot$  Beta Thalassemia major  $\cdot$  Cousins

Saif-ur-Rehman Saif Abbasi saif\_abbasi2002@yahoo.com

Malik Maliha Manzoor malihamanzoor18@gmail.com

<sup>1</sup> Department of Social Sciences, Shaheed Zulfikar Ali Bhutto Institute of Science and Technology, Islamabad, Pakistan

Muhammad Abo ul Hassan Rashid hassan.rashid@szabist-isb.edu.pk

<sup>&</sup>lt;sup>2</sup> International Islamic University Islamabad, Islamabad, Pakistan

#### Introduction

Thalassemia is a serious public health problem across the world, particularly in developing countries. This disease has various forms. Two among these forms, which are termed as alpha and beta, are most common (Mettananda et al. 2015). Moreover, in either of these two forms of thalassemia, hemoglobin, which carries oxygen to all the cells in a human body, is affected (Greenburg 2009).

Studies show the propagation of beta thalassemia major to be a serious threat to the middle- and low-income countries across the world (Khalid et al. 2019). The disease imposes intensive psychosocial burden on parents and children. Researches find that parents and children with beta thalassemia major experience a significant psychological maladjustment (Joshi and Vashist 2018; Mettananda et al. 2019). However, most of these researches (Lomas 1998; McEwen and Wills 2017; Moghavvemi et al. 2017) have been conducted in biomedical sciences, and thus, they have focused on biological aspects of this disease and its epidemiological postures rather than exploring any social, cultural, and religious factors associated with it (Hossain et al. 2017; Smith and Praetorius 2019).

#### Parental Knowledge

Lack of education and awareness about thalassemia is a major non-biomedical factor, which leads families to face serious social, economic, and psychological problems (Ebrahim et al. 2019). Researches (Piel and Weatherall 2014; Radke et al. 2019) found that lack of knowledge about the disease, health facilities such as medicalization and counseling, and associated psychological and cultural issues impede the maintenance of healthcare.

Therefore, awareness and attitude towards screening practices for the treatment of disease depend upon the level of awareness and education of the families concerned about the disease (Thiyagarajan et al. 2019) because without appropriate knowledge of the causes of the disease, preventions and remedies remain ineffective. Moreover, without adequate relevant knowledge and understanding, one fails to differentiate between thalassemia major, thalassemia minor and the carriers of this disease as well. Additionally, inheritance patterns are also difficult to be discerned without due knowledge and understanding of the disease. The failure in discerning these inheritance patterns causes an immense physical as well as social impact in the form of disorder(s) on affected patients and their families (Zaheer et al. 2015). An adequate knowledge and awareness at public level coupled with a trained general social attitude towards these issues of thalassemia have proved an important measure against the propagation of thalassemia since ancient times (Politis et al. 1991).

#### Social Factors of Beta Thalassemia Major

The attitude of a family, especially in traditional societies particularly in rural areas, is mainly determined by social, cultural and religious factors (Furnham 2015; Tokur-Kesgin et al. 2019). These factors shape the living patterns and life styles of the

inhabitants in such communities. Therefore, individuals in such communities cope with the challenges of thalassemia under prevalent social attitudes practices. Any innovate strategy adopted at individual level may come into conflict with the local interpretations and practices of religion (Chong et al. 2019).

Moreover, like many other chronic illnesses, patients of thalassemia and their families required meticulous support from relatives, health professionals and from rest of the community members to manage their psychological and social maladjustment. Studies (Patel et al. 2019) reflect that a family is believed to be the primary and most important source of social support for patients and their parents to mitigate the psychological and social burden caused by thalassemia. Patients of thalassemia are required medical as well as social support from their families, medical professionals and other community members for their social adjustment. Similarly, preventions against thalassemia also need moral, social and medical support to the affected children and their families. Moreover, the effective management and social support also largely depends upon general knowledge about the disease; therefore, the general population of any area needs at least relevant basic awareness and education (Kelsey 2015).

#### **Religious Factors of Beta Thalassemia Major**

Studies (Cremonini et al. 2009; Katz et al. 2017; Nutini and Bell 2019) emphasize that the cultural and religious factors are major variables that determine an individual's choices and decisions about his life. Hence, these factors significantly shape people's choices and preferences of medication and treatment of beta thalassemia major (Adly and Ebeid 2015).

Although termination of pregnancy is an acceptable way in Islam and Muslim community can follow the certain instructions, that are very clear in *Fatwa* (before 120 days of gestation, a fetus can be terminated in case of having any chronic illness, that might cause death or any other serious complication for mother or new born) (Iqbal et al. 2019). Having clear religious instructions, nobody can blame the true spirit of any religion including Islam, for the treatment of any chronic disease. These are only myths and synthesis that blame religious true spirit and retain individuals to choose scientific ways to handle such chronic ailments (Alkali et al. 2015).

#### Psychosocial Burden of Beta Thalassemia Major

Parents and family members of those children who are suffering with beta thalassemia major face acute depression and anxiety (Kermansaravi et al. 2018). Such feelings originated from the perception that beta thalassemia major is a life sacking disease may ultimately result in a general pessimism about life in the suffering children and their families as well (Mohamadian et al. 2018). Moreover, this pessimistic attitude is also significantly aggravated by stigmatization developed about Beta thalassemia major (Moudi et al. 2019).

Beta thalassemia major also creates the feelings of denial, withdrawal and lack of acceptance of the consequences of disease, among parents and families of

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thalassemic children (Chan et al. 2017). The disease creates emotional and psychological trepidation among parents of sick children because of its ominous repercussions. Moreover, psychological impact of this disease immensely mars the recreational and aesthetic aspects of life of the affected children and significantly disrupts educational activities such as school timings (Khanna et al. 2015). In the same way, beta thalassemia major has also a negative impact on sexual and physical growth of sick children because of abnormal hormonal growth and lack of healthy diet, along with iron overload due to excessive blood transfusion (Khanna et al. 2015).

#### Social Model of Health and Illness

After the dominant criticism on the existing biomedical model in twenty-first century, the literature drew attention of health experts and medical scientists to integrate social causes for the prevention of this disease of beta thalassemia major. Social narratives highlighted the cultural, religious, communal and familial practices, which shape the health of any individual and the practices to avoid any health issue. These social perceptions included health and hygiene, marriage practices, and psychological aspects. Others focused on medicines and clinical experiments, which were dominant in earlier model. The social model included the social and cultural aspects that shape the maintenance or disruption of health. It viewed health in connection with the continuous process of individual, cultural and social practices (Fried et al. 2004). From *Weberian* explanation of life chances and choices (Cockerham et al. 1993) to sick role of (Parsons 1951), health and illness have been conceptualized differently across the world (Larson 1999). Moreover, the universal agreement on the definition of health still remains unsettled (Zautra et al. 2010) because the social and cultural practices and understandings are not identical.

The social model interprets biological mechanisms in terms of social causes. It explains being healthy and unhealthy on the basis of social explanations. The model contextualizes health as an amalgamation of social factors including socioeconomic status, cultural practices, sanitation and hygiene. The proponents of this social model (Anastasiou and Kauffman 2011; Ghaemi 2009) emphasize that the understanding of health and illness depends on the understanding of social aspects including poverty, awareness, parental practices, ethnic and cultural practices and religious beliefs which, they think, largely determines medical realities. This social model considers mental and psychological factors equally important because, accordingly to this model, these factors significantly prove not only as the consequences of any disease but its causes as well (Kawachi and Berkman 2001).

In the context of thalassemia generally and beta thalassemia major particularly, the theoretical orientations incorporated by many researchers (Fibach et al. 2012; Auger and Pennell 2016) are highly influenced by biomedical model of health and illness. Although the disease prompts due to biological abnormalities of human globin and transmits from parents to their children but there are numerous social factors which contribute to the prevalence of thalassemia along with the outcomes such as psychological abnormalities and physical disabilities (Messina et al. 2008). Social Model of health and illness which aims to denote the attention of researchers and

policy makers towards the social causes and practices of any biological disorder or epidemic, encompasses social factors including socioeconomic status, cultural practices, sanitation and hygiene to determine the state of being healthy or not (Rashid and Abbasi 2020). The prevalence of thalassemia highly depends upon consanguineous marriages, traditional/religious beliefs and practices for the management and treatment of disease (Platania et al. 2017). The effective mitigation of the disease can be acquired by addressing social, cultural and religious beliefs and practices across the world and especially in rural and traditional communities of Pakistan, India, Bangladesh, Saudi Arabia, Iran and Iraq and among many other countries which are facing increasing rate of beta thalassemia major.

#### Methodology

The study focuses on the province of Punjab in Pakistan. It collected data for its analysis from 3 different blood transfusion centers which are *Jamila Sultana Foundation*, *Fatimid Foundation and Sundas Foundation*. The participants were 932 parents of children suffering from beta thalassemia major. This data was selected with the help of Taro Yamane (1973:258) formula, which is commonly used in social sciences to calculate sample sizes (Eckhardt and Ermann 1977; Songkram et al. 2015; Yamane 1973). The formula is explained below:

$$n = \frac{N}{1 + N(e^2)}$$

*n* sample size; *N* total population; *e* margin of error.

The total population of this study was 5597 patients which is denoted by N, while e is known as margin of the error and commonly used as .05. The margin of error used in this study was .03 which is less than the common maximum range. The sample size, which is denoted by n, was 932, which was finally selected by planned methodology of this study.

#### **Selection of the Respondents**

The study population consisted of the parents of those children who were suffering from Beta Thalassemia Major. The selection of the respondents was based on the following criteria by applying random sampling method:

- 1. Parents of the patients were selected from the province of Punjab in Pakistan.
- 2. All these were the parents of those children who were diagnosed as the patients of Beta Thalassemia Major.
- 3. All these parents of only those children, who were not suffering from any other genetic disorder.
- 4. Parents of those children, who were not suffering from any other illness

#### **Tool of Data Collection**

Data was collected by using interview schedule as a tool which comprised demographic variables, independent factors (parental knowledge of disease, social and religious factors) and dependent variable (psychosocial burden of beta thalassemia major).

# Variables and Measurement

Parental knowledge of beta thalassemia major comprised 16 items. It was used as a computed variable in the both models. The variable was measured by using 5 Likert Scale. Social factors of beta thalassemia major were based on 10 items, though significant predictors of psychosocial burden among non-cousin couples (M9) were only four social factors (marriage breakups, beliefs in unnatural forces, stigmatization, and social support). However, psychosocial burden among cousin couples (M10) was predicted by five social factors (patriarchy was a fifth factor). The study employed three religious predictors (religious restrictions regarding termination of pregnancy, beliefs regarding prevention and encouragement of consanguineous marriages) in both models, out of eight items.

To measure the psychosocial burden of thalassemia on patient's parents an interview schedule "psychosocial burden of thalassemia" by Canatan et al. (2003) was adapted. This interview schedule consisted of total 16 items to measure the burden (psychosocial) on patient's parent. The items of were rated on 5 Likert Scale (SA=Strongly Agree, A=Agree, U=Undecided, D=Disagree, SD=Strongly Disagree). However, the variable in model was employed as a computed variable. The reliability of the interview schedule, used for the measurement of dependent variable was .8051, which was measured using Cronbach alpha. The statements used for the measurement of dependent variable 1.

# **Ethical Consideration**

The data of present study was collected with the permission of competent authorities of thalassemia foundations. The parents of sick children were also ensured that their personal information would not be sold or revealed for any commercial purpose. They were briefed about the nature of the study for which they were surveyed. Moreover, their written consent was also obtained to ensure the ethical practices of public health.

lable I Cronoach alpha values of psychosocial burden					
Variable	Mean	SD	Total Mean	Total SD	Alpha
Thalassemia is affecting education of your child	3.786481	1.253356	54.93562	9.202703	.8072
There is a significant effect of thalassemia on school timing of your child	3.339056	1.200992	55.38305	9.245561	.8080
Your child can participate in sport	2.084764	.9409548	56.63734	9.574594	.8193
You usually feel a certain level of anxiety due to the bad health of your child	3.991416	1.14845	54.73069	8.771194	1777.
You have weak family interactions due to your thalassemic child	3.651288	1.356715	55.07082	8.703329	8677.
You feel social isolation due to your thalassemic child	4.110515	.999257	54.61159	9.47479	.8153
Thalassemia have a significant effect on your social life	3.651288	1.356715	55.07082	8.703329	8677.
Your child can have the feelings of difference due his/her disease	3.651288	1.356715	55.07082	8.703329	8677.
Your child can have social stigmatization due to thalassemia	3.651288	1.356715	55.07082	8.703329	8677.
Your child has a high-level social integration	3.061159	.9518561	55.66095	9.492314	.8152
Your child is facing bad expression of self-image	3.991416	1.14845	54.73069	8.771194	1777.
You have the feelings of denial	3.991416	1.14845	54.73069	8.771194	1777.
You feel confusion	3.991416	1.14845	54.73069	8.771194	.7771
You have feelings of guilt	3.991416	1.14845	54.73069	8.771194	.7771
You have weak social integration	3.596566	1.382066	55.12554	9.286021	.8162
Thalassemia effected/effect your family size	4.181331	.8857114	54.54077	9.43856	.8108
Total			58.7221	9.570195	.8051

Table 1 Cronbach alpha values of psychosocial burden

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# Results

Socioeconomic status includes age, education, monthly family income and expenditures (Baker 2014). The present study measured the ages (now and at the time of their marriages) of mother(s) and father(s) along with their education, monthly income and expenditures of entire family including the particular expenditures for the treatment of beta thalassemia major.

## Descriptive Statistics of Socioeconomic Status of Respondents and their Spouses

Descriptive statistics are tabulated in Table 2. The data reveals that average age is 36 and 33 years of father(s) and mother(s) of the children suffering from beta thalassemia major respectively. The average age at the time of marriages has also been recorded in the Table 2 (Father's age=24 and Mother's age=21). The study showed the average, minimum and maximum educational level of both parents. It also revealed that majority of the parents (Father, n=150 and Mother, n=168) were uneducated, while the highest educational level of father's was MS/M. Phil degree (n=1). Overall, as the education level of mothers was found higher than that of fathers because 21 mothers had 16 years education.

The average monthly income of respondent's was 29482 PKR (approximately 182 USD), while the expenditures were 22633 PKR (approximately 139 USD). The study also found that the difference between income and expenditures of a family was due to the disease of a child because the parents were averagely spending 5336 (approximately 33 USD).

Moreover, due to cultural practices, especially endogamy, in Pakistan, majority of the respondents (78.9%) were married with cousins, while only (21.1%) were married out of their families. These findings agree with those reflected in the study of (Khan et al. 2015), which show that out of 180 respondents, 133 (74%) of the respondents were married with their cousins and that due to this higher rate of cousin marriages, beta thalassemia major was alarmingly propagating. Another

Variables	Mean	Minimum	Maximum
Father's age	36	20(n=5)	60 (n = 12)
Mother's age	33	18(n=1)	62(n=6)
Father's age at the time of marriage	24	14(n=4)	35 ( <i>n</i> =41)
Mother's age at the time of marriage	21	12(n=1)	35(n=6)
Father's education	8	0 (n = 150)	18(n=1)
Mother's education	6	0(n = 168)	16 ( <i>n</i> =21)
Monthly family income	29482	5000 (n=2)	100000 (n=12)
Monthly family expenditures	22633	2000 (n=2)	80000 (n=1)
Monthly expenditures on medications	5336	500 (n=37)	20000 (n=6)

Table 2 Descriptive Statistics of Socioeconomic Status of Respondents and their Spouses

Married with cousins = 735, Not married with cousins = 197

study (Ishaq et al. 2012) also found as many as 81.7% cousin marriages among its respondents.

# Predictors of Psychosocial Burden of Beta Thalassemia Major in Non-cousin Marriage (M9)

Table 3 reveals the data of predictors of psychosocial burden of beta thalassemia major in non-cousin couples (respondents). Using stepwise (forwards method) multiple linear regression technique, the final model (M9) figured out eight significant predictors of outcome variable (psychosocial burden). Data reveals that 39.4% variation of outcome variable has been explained by the eight significant predictors ( $R^2$ =.394). Furthermore, parental knowledge of beta thalassemia major, social support and religious encouragement regarding cousin marriages were significantly negative predictors of psychosocial burden of beta thalassemia major in non-cousin couples (B=-.181)\*\* (B=-.333)\* and (B=-.222)\* respectively. However, parents beliefs regarding marital breakup (B=.272)\*, believes in unnatural forces to be the cause of beta thalassemia major (B=.449)\*\*, feeling of stigmatization (B=.479)\*\*, religious restrictions regarding termination of pregnancy (B=.610)\*\* and religious beliefs regarding prevention of the disease (B=.482)\*\* were significantly positive predictors of psychosocial burden of beta thalassemia major among non-cousin couples.

Model	Unstandardized coef- ficients		Т	р
	В	SE		
(Constant)	20.003	.736	27.177	.000
Parental knowledge	181	.019	-9.672	.000
MB	.272	.094	2.910	.004
BUF	.449	.104	4.305	.000
Stigmatization	.479	.109	4.375	.000
Social support	333	.105	-3.164	.002
RRTP	.610	.100	6.072	.000
RBP	.482	.109	4.415	.000
RECM	222	.104	-2.128	.034
$R^2$	(.394)			
Adj. R <sup>2</sup>	(.291)			
$\Delta R^2$	(.004)			
F	(18.879)**			
$\Delta F$	(4.530)			

\*p < .05, \*\*p < .001, MB=Marital breakup, BUF=Beliefs in unnatural forces, RRTP=Religious restriction regarding termination of pregnancy, RBP=Religious believes regarding prevention, RECM=Religion encouragement regarding cousin marriages

Table 3Predictors ofpsychosocial burden of betaThalassemia major in non-cousin marriage (M9)

# Predictors of Psychosocial Burden of Beta Thalassemia Major in Cousin Marriage (M10)

Data enclosed in Table 4 reveals the predictors of psychosocial burden of beta thalassemia major among cousin couples (respondents). Using stepwise (forwards method) multiple linear regression technique, the final model (M10) figured out nine significant predictors of outcome variable (psychosocial burden). Data shows that 32.6% variation of psychosocial burden of beta thalassemia major, among cousin couples has been explained by these nine predictors. Furthermore, parental knowledge regarding beta thalassemia major (B = -.123)\*\*, social support (B = -.496)\* and religious encouragement regarding termination of pregnancy (B = -.315)\*, were significantly negative predictors of outcome variable. However, couples believe regarding marital breakups (B = .347)\*, beliefs in unnatural forces (B = .413)\*, stigmatization (B = .409)\*, patriarchy (B = -.186)\*, religious restrictions regarding termination of pregnancy (B = .366)\* were significantly positive predictors of psychosocial burden of beta thalassemia major (B = .366)\* were significantly positive predictors of psychosocial burden of beta thalassemia major (B = .366)\* were significantly positive predictors of psychosocial burden of beta thalassemia major (B = .366)\* were significantly positive predictors of psychosocial burden of beta thalassemia major (B = .366)\* were significantly positive predictors of psychosocial burden of beta thalassemia major among cousin couples.

Model	Unstandardized Coef- ficients		t	р
	B	SE		
(Constant)	20.545	.891	23.052	.000
Parental Knowledge	123	.029	-4.194	.000
MB	.347	.109	3.170	.002
BUF	.413	.129	3.192	.001
Stigmatization	.409	.128	3.202	.001
Social support	496	.132	-3.750	.000
Patriarchy	.186	.134	1.391	.165
RRTP	.499	.125	3.987	.000
RBP	.366	.137	2.678	.008
RECM	315	.131	-2.398	.017
$R^2$	(.326)			
Adj R <sup>2</sup>	(.280)			
$\Delta R^2$	(.007)			
F	(8.635)**			
$\Delta F$	(5.752)			

\*p < .05, \*\*p < .001

*MB* marital break-up; *BUF* beliefs in unnatural forces; *RRTP* religious restriction regarding termination of pregnancy; *RBP* religious believes regarding prevention; *RECM* religion encouragement regarding cousin marriages

Table 4Predictors ofpsychosocial burden of betaThalassemia major in cousinmarriage (M10)

# Discussion

The previous studies conducted by (Alswaidi et al. 2012; Memish and Saeedi 2011) focused on social and religious factors which propagate beta thalassemia major and caused serious economic, social and psychological burden on parents of sick children (Prasomsuk et al. 2007). It has also been intensively studied that cousin marriages are the major reasons of beta thalassemia major (Ayub et al. 2017; Faizan-ul-Haq et al. 2016). The researchers (Ishfaq et al. 2015; Muhammad et al. 2017) kept their focus rigorously to study consanguinities and beta thalassemia major but none of them figured out the effect of social, cultural and religious factors on psychosocial burden of beta thalassemia major on cousins and non-cousin couples distinctively.

The study found that role of patriarchy is a significant factor among cousin couples. This role of patriarchy was found to be positively affecting the psychosocial burden of beta thalassemia major among cousin couples. The study also revealed that parental knowledge of disease has a significant effect on psychosocial burden of beta thalassemia major among both cousin and non-cousins couples. The effective management and prevention of thalassemia requires comprehensive understanding and knowledge about beta thalassemia major (Elewa and Elkattan 2017; Rund and Rachmilewitz 2005). The lack of knowledge and awareness regarding causes and management of beta thalassemia major, not only aggravates the disease but has a strong impact on social and psychological adjustment of parents of sick children (Abu Shosha and Al Kalaldeh 2018).

Parental maladjustment due to continuous stress and social pressure imposes a negative effect on their quality of life (Mettananda et al. 2019; Tomaj et al. 2016) and social adjustment (Inamdar et al. 2015). Strong emphasize on endogamy and cultural practices for marriages restrain couples and families to follow precise management practices for the treatment of beta thalassemia major (Bener et al. 2019) and they avoid pre/postnatal diagnosis and genetic screening methods (Antonarakis 2019). As a result, the genetic abnormality (beta thalassemia major) prompts over the large scale across the world. It has been generally estimated that, every year 50 thousand to 1 lack children, living in the low and middle income countries die because of this chronic genetic aliment (beta thalassemia major), however, an estimated population of 7% in the entire world is the carrier of hemoglobin disorder in the form of beta thalassemia major (Arif et al. 2008).

Lack of social support has also been seen to be a significant factor, which increases psychosocial burden of the disease (Palanisamy et al. 2017). Like many other chronic illnesses, patients of thalassemia and their families required meticulous support from relatives, health professionals and from rest of the community members to manage their psychological and social maladjustment. It has been investigated by researchers (Patel et al. 2019) that family is believed to be the primary and most important source of social support for patients and their parents to mitigate the psychological and social burden caused by thalassemia. Patients of thalassemia are required medical as well as social support from their families, medical professionals and other community members for their social adjustment

and confrontation against thalassemia requires moral, social and medical support to the children and their families. The effective management and social support also required general knowledge about the disease, so the general population of any area required to gain at least the basic (Kelsey 2015).

# Conclusion

In many rural areas of Pakistan, due to traditional cultural practices, blind religious believes, ignorance and pressure from family and society, parents of thalassemic child face many problems in the treatment of their sick child (Aziz et al. 2012) along with their social adjustment (Shaligram et al. 2007). Beside medical and professional support, these people required awareness, acceptance, recognition and removal of social pressure to manage the disease and knob these decisive circumstances (Roy and Chatterjee 2007). Social support and strong ties among communities have positive impact on children's health, development and wellbeing (Palanisamy et al. 2017). In case of thalassemia these strong ties and enriched social support is very helpful to manage thalassemia very effectively and which can be seen among rural communities of Pakistan but parents of thalassemic children are facing stigmatization and social isolation because of lack of education and awareness of causes and propagation of thalassemia (Hussein et al. 2018). A range of psychological and social maladjustment have been premeditated among the parents of thalassemic children, that includes; social isolation, stigmatization, anxiety and depression (Mufti et al. 2015). The accentuate on reducing social and psychological burden requires effective parental knowledge for the management and prevention of thalassemia (Maheen et al. 2015), strong social support (Messina et al. 2008), elimination of social stigma (Pouraboli 2019) and patriarchy (Raffa 2019), along with the awareness of religious believes (Punaglom et al. 2019).

#### Limitation and Future Directions

The present study was conducted at selected centers of blood transfusion in Punjab Province covering only the registered patients, which limits the scope of study in terms of territorial coverage. The future studies may cover other provinces and patients of beta thalassemia minor for comparative analysis.

#### Compliance with Ethical Standards

**Conflict of interest** The undersigned with the consent of all the authors, declare that they have no conflict of interest for submission and publication of this manuscript in "Journal of Religion and Health'.

Human and Animals Rights The parents of thalassemic children were interviewed, for this purpose the methodology and tool of data collection was approved by the ethical review board of the International Islamic University, Islamabad.

**Informed Consent** Before data collection, the informed consent of parents and authorities of blood transfusion centers was obtained.

# References

- Abu Shosha, G., & Al Kalaldeh, M. (2018). Challenges of having a child with Thalassaemia major: A phenomenological study. *Journal of Research in Nursing*, 23(1), 9–20.
- Adly, A. A., & Ebeid, F. S. E. S. (2015). Cultural preferences and limited public resources influence the spectrum of thalassemia in Egypt. *Journal of Pediatric Hematology/Oncology*, 37(4), 281–284.
- Alkali, A. U., binti Mohd, A., Hak, N. A., & Soh, R. C. (2015). Abortion: An infringement of the foetus'right to life in Islamic law. *IIUM Law Journal*, 23(1), 1.
- Alswaidi, F. M., Memish, Z. A., O'Brien, S. J., Al-Hamdan, N. A., Al-Enzy, F. M., Alhayani, O. A., et al. (2012). At-risk marriages after compulsory premarital testing and counseling for β-thalassemia and sickle cell disease in Saudi Arabia, 2005–2006. *Journal of Genetic Counseling*, 21(2), 243–255.
- Anastasiou, D., & Kauffman, J. M. (2011). A social constructionist approach to disability: Implications for special education. *Exceptional Children*, 77(3), 367–384.
- Antonarakis, S. E. (2019). Carrier screening for recessive disorders. Nature Reviews Genetics, 20(9), 549–561.
- Arif, F., Fayyaz, J., & Hamid, A. (2008). Awareness among parents of children with thalassemia major. J Pak Med Assoc, 58(11), 621–624.
- Auger, D., & Pennell, D. J. (2016). Cardiac complications in thalassemia major. Annals of the New York Academy of Sciences, 1368(1), 56–64.
- Ayub, R., Khan, H. M., ur Rehman, Z., Ahsan, J., Gul, R., Khan, U., et al. (2017). Prevention of Thalassemia. *The Professional Medical Journal*, 24(02), 249–251.
- Aziz, K., Sadaf, B., & Kanwal, S. (2012). Psychosocial problems of Pakistani parents of Thalassemic children: A cross sectional study done in Bahawalpur, Pakistan. *BioPsychoSocial medicine*, 6(1), 15.
- Baker, E. H. (2014). Socioeconomic status, definition. In The Wiley Blackwell Encyclopedia of health, illness, behavior, and society (pp. 2210–2214).
- Bener, A., Al-Mulla, M., & Clarke, A. (2019). Premarital screening and genetic counseling program: Studies from an endogamous population. *International Journal of Applied and Basic Medical Research*, 9(1), 20.
- Canatan, D., Ratip, S., Kaptan, S., & Cosan, R. (2003). Psychosocial burden of β-thalassaemia major in Antalya, South Turkey. Social science & medicine, 56(4), 815–819.
- Chan, Y. M., Chan, O. K., Cheng, Y. K. Y., Leung, T. Y., Lao, T. T. H., & Sahota, D. S. (2017). Acceptance towards giving birth to a child with beta-thalassemia major–A prospective study. *Taiwanese Journal of Obstetrics and Gynecology*, 56(5), 618–621.
- Chong, T. L., Chong, C. M., Tang, Y. L., Ramoo, V., Chui, L. P., & Hmwe, N. T. T. (2019). The relationship between psychological distress and religious practices and coping in Malaysian parents of children with Thalassemia. *Journal of Pediatric Nursing*, 48, 15–20.
- Cockerham, W. C., Abel, T., & Lüschen, G. (1993). Max weber, formal rationality, and health lifestyles. Sociological Quarterly, 34(3), 413–425.
- Cremonini, L., Westerheijden, D., & Enders, J. (2009). Disseminating the right information to the right audience: Cultural determinants in the use (and misuse) of rankings In *University Rankings, Diversity, and the New Landscape of Higher Education* (pp. 65-81): Brill Sense.
- Ebrahim, S., Raza, A. Z., Hussain, M., Khan, A., Kumari, L., Rasheed, R., et al. (2019). Knowledge and beliefs regarding Thalassemia in an Urban population. *Cureus*, 11(7), 1.
- Eckhardt, K. W., & Ermann, M. D. (1977). Social research methods: Perspective, theory, and analysis. New York: Random House.
- Elewa, A., & Elkattan, B. (2017). Effect of an educational program on improving quality of nursing care of patients with thalassemia major as regards blood transfusion. *American Journal of Nursing Research*, 5(1), 13–21.
- Faizan-ul-Haq, M. M., Khan, M. M. A., Sajid, S., Sarfaraz, A., Nasir, N., Nazim, A., et al. (2016). Frequency and awareness of Thalassemia in families with cousin marriages: A study from Karachi, Pakistan. In *Paper presented at the 14th International Conference on*.

- Fibach, E., Prus, E., Bianchi, N., Zuccato, C., Breveglieri, G., Salvatori, F., et al. (2012). Resveratrol: Antioxidant activity and induction of fetal hemoglobin in erythroid cells from normal donors and β-thalassemia patients. *International Journal of Molecular Medicine*, 29(6), 974–982.
- Fried, L. P., Carlson, M. C., Freedman, M., Frick, K. D., Glass, T. A., Hill, J., et al. (2004). A social model for health promotion for an aging population: initial evidence on the Experience Corps model. *Journal of Urban Health*, 81(1), 64–78.
- Furnham, A. (2015). Young people's understanding of society (Routledge Revivals). London: Routledge.
- Ghaemi, S. N. (2009). The rise and fall of the biopsychosocial model. *The British Journal of Psychiatry*, 195(1), 3–4.
- Greenburg, A. G. (2009). The ideal blood substitute. Critical Care Clinics, 25(2), 415-424.
- Hossain, M. S., Raheem, E., Sultana, T. A., Ferdous, S., Nahar, N., Islam, S., et al. (2017). Thalassemias in South Asia: clinical lessons learnt from Bangladesh. *Orphanet Journal of Rare Diseases*, 12(1), 93.
- Hussein, N., Weng, S. F., Kai, J., Kleijnen, J., & Qureshi, N. (2018). Preconception risk assessment for thalassaemia, sickle cell disease, cystic fibrosis and Tay-Sachs disease. *Cochrane Database of Systematic Reviews*, 3, 1.
- Inamdar, S., Inamdar, M., & Gangrade, A. (2015). Stress level among caregivers of thalassemia patients. *Community Med*, 6(4), 578–579.
- Iqbal, H., Habib, A., & Amer, S. (2019). Abortion-An Islamic perspective. Ethics, 2(1), 1.
- Ishaq, F., Hasnain Abid, F., Akhtar, A., & Mahmood, S. (2012). Awareness among parents of ββ-Thalassemia major patients, regarding prenatal diagnosis and premarital screening. *Journal of the College of Physicians and Surgeons Pakistan*, 22(4), 218–221.
- Ishfaq, K., Shabbir, M., Naeem, S. B., & Hussain, S. (2015). Impact of Thalassemia major on patients. *The Professional Medical Journal*, 22(05), 582–589.
- Joshi, P., & Vashist, N. (2018). Illness, Health and Culture: Anthropological Perspectives on Ethno-Medicine in India. In Psychosocial interventions for health and well-being (pp. 227–240). Springer.
- Katz, E., Lazarsfeld, P. F., & Roper, E. (2017). Personal influence: The part played by people in the flow of mass communications. London: Routledge.
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. Journal of Urban Health, 78(3), 458–467.
- Kelsey, J. (2015). Nurses' knowledge and role in the management of Thalassemic patients in Sulaimania Thalassemia Center. *Iraqi National Journal of Nursing Specialties*, 2(28), 59–70.
- Kermansaravi, F., Najafi, F., & Rigi, S. (2018). Coping behaviors in parents of children with Thalassemia major. *Medical-Surgical Nursing Journal*, 7(1), 1.
- Khalid, S., Hamid, S., Goldman, R., Mubarik, H., Yaqub, N., Khan, S., et al. (2019). Impact of bone marrow transplant vs. supportive care on health related quality of life in patients with severe Thalassemia in a lower middle-income country. *Biology of Blood and Marrow Transplantation*, 25(3), S69.
- Khan, M. S., Ahmed, M., Khan, R. A., Mushtaq, N., & Wasim, M. U. S. (2015). Consanguinity ratio in b-thalassemia major patients in District Bannu. JPMA The Journal of the Pakistan Medical Association, 65(11), 1161–1163.
- Khanna, A. K., Prabhakaran, A., Patel, P., Ganjiwale, J. D., & Nimbalkar, S. M. (2015). Social, psychological and financial burden on caregivers of children with chronic illness: A cross-sectional study. *The Indian Journal of Pediatrics*, 82(11), 1006–1011.
- Larson, J. S. (1999). The conceptualization of health. *Medical Care Research and Review*, 56(2), 123-136.
- Lomas, J. (1998). Social capital and health: Implications for public health and epidemiology. Social Science and Medicine, 47(9), 1181–1188.
- Maheen, H., Malik, F., Siddique, B., & Qidwai, A. (2015). Assessing parental knowledge about thalassemia in a thalassemia center of Karachi, Pakistan. *Journal of genetic counseling*, 24(6), 945–951.
- McEwen, M., & Wills, E. M. (2017). Theoretical basis for nursing. Philadelphia: Lippincott Williams & Wilkins.
- Memish, Z. A., & Saeedi, M. Y. (2011). Six-year outcome of the national premarital screening and genetic counseling program for sickle cell disease and β-thalassemia in Saudi Arabia. Annals of Saudi Medicine, 31(3), 229–235.
- Messina, G., Colombo, E., Cassinerio, E., Ferri, F., Curti, R., Altamura, C., et al. (2008). Psychosocial aspects and psychiatric disorders in young adult with thalassemia major. *Internal and Emergency Medicine*, 3(4), 339.

- Mettananda, S., Gibbons, R. J., & Higgs, D. R. (2015). α-Globin as a molecular target in the treatment of β-thalassemia. Blood, The Journal of the American Society of Hematology, 125(24), 3694–3701.
- Mettananda, S., Pathiraja, H., Peiris, R., Bandara, D., de Silva, U., Mettananda, C., et al. (2019). Health related quality of life among children with transfusion dependent  $\beta$ -thalassaemia major and haemoglobin E  $\beta$ -thalassaemia in Sri Lanka: a case control study. *Health and quality of life outcomes*, 17(1), 137.
- Moghavvemi, S., Ormond, M., Musa, G., Isa, C. R. M., Thirumoorthi, T., Mustapha, M. Z. B., et al. (2017). Connecting with prospective medical tourists online: A cross-sectional analysis of private hospital websites promoting medical tourism in India, Malaysia and Thailand. *Tourism Management*, 58, 154–163.
- Mohamadian, F., Bagheri, M., Hashemi, M. S., & Sani, H. K. (2018). The effects of cognitive behavioral therapy on depression and anxiety among patients with thalassemia: A randomized controlled trial. *Journal of caring sciences*, 7(4), 219.
- Moudi, Z., Phanodi, Z., & Vedadhir, A. (2019). Sin and suffering: Pregnant women's justifications for deciding on pregnancy termination due to beta-thalassemia major in Southeast of Iran. *Nursing and Midwifery Studies*, 8(2), 91–96.
- Mufti, G.-E.-R., Towell, T., & Cartwright, T. (2015). Pakistani children's experiences of growing up with beta-thalassemia major. *Qualitative Health Research*, 25(3), 386–396.
- Muhammad, R., Shakeel, M., Rehman, S. U., & Lodhi, M. A. (2017). Population-based genetic study of β-thalassemia mutations in Mardan Division, Khyber Pakhtunkhwa Province, Pakistan. *Hemoglobin*, 41(2), 104–109.
- Nutini, H. G., & Bell, B. (2019). Ritual Kinship, Volume I: The Structure and Historical Development of the Compadrazgo System in Rural Tlaxcala (Vol. 5468): Princeton University Press.
- Palanisamy, B., Kosalram, K., & Gopichandran, V. (2017). Dimensions of social capital of families with thalassemia in an indigenous population in Tamil Nadu, India–a qualitative study. *International Journal for Equity in Health*, 16(1), 109.
- Parsons, T. (1951). Illness and the role of the physician: A sociological perspective. American Journal of Orthopsychiatry, 21(3), 452–460.
- Patel, P., Beamish, P., da Silva, T. L., Kaushalya, D., Premawardhena, A., Williams, S., et al. (2019). Examining depression and quality of life in patients with thalassemia in Sri Lanka. *International Journal of Noncommunicable Diseases*, 4(1), 27.
- Piel, F. B., & Weatherall, D. J. (2014). The α-thalassemias. New England Journal of Medicine, 371(20), 1908–1916.
- Platania, S., Gruttadauria, S., Citelli, G., Giambrone, L., & Di Nuovo, S. (2017). Associations of Thalassemia major and satisfaction with quality of life: The mediating effect of social support. *Health Psychology Open*, 4(2), 2055102917742054.
- Politis, C., Richardson, C., & Yfantopoulos, J. G. (1991). Public knowledge of thalassemia in Greece and current concepts of the social status of the thalassemic patients. *Social Science and Medicine*, 32(1), 59–64.
- Pouraboli, B. (2019). Living in Darkness and Lightness: Experiences of Thalassemia Patients and their Caregivers in South East Iran. *i-Manager's Journal on Nursing*, 9(3), 8.
- Prasomsuk, S., Jetsrisuparp, A., Ratanasiri, T., & Ratanasiri, A. (2007). Lived experiences of mothers caring for children with thalassemia major in Thailand. *Journal for Specialists in Pediatric Nursing*, 12(1), 13–23.
- Punaglom, N., Kongvattananon, P., & Somprasert, C. (2019). Experience of parents caring for their children with Thalassemia: Challenges and issues for integrative review. *The Bangkok Medical Journal*, 15(1), 1.
- Radke, T., Paulukonis, S., Hulihan, M. M., & Feuchtbaum, L. (2019). Providers' perspectives on treating patients with Thalassemia. *Journal of Pediatric Hematology/oncology*, 41(7), e421–e426.
- Raffa, V. (2019). Thalassemic women's biographical trajectory: Retracing gender inequalities in health policies. Underserved and Socially Disadvantaged Groups and Linkages with Health and Health Care Differentials (Research in the Sociology of Health Care), 37, 189–201.
- Rashid, M. A. U. H., & Abbasi, S. U. R. S. (2020). Theorizing beta Thalassemia major: An overview of health sociology. *International and Multidisciplinary Journal of Social Sciences*, 9(1), 1.
- Roy, T., & Chatterjee, S. C. (2007). The experiences of adolescents with thalassemia in West Bengal, India. *Qualitative Health Research*, 17(1), 85–93.
- Rund, D., & Rachmilewitz, E. (2005). β-Thalassemia. New England Journal of Medicine, 353(11), 1135–1146.

- Shaligram, D., Girimaji, S., & Chaturvedi, S. (2007). Psychological problems and quality of life in children with Thalassemia. *The Indian Journal of Pediatrics*, 74(8), 727–730.
- Smith, M., & Praetorius, R. T. (2019). College students' knowledge about sickle cell disease. Journal of Human Behavior in the Social Environment, 29(3), 308–320.
- Songkram, N., Khlaisang, J., Puthaseranee, B., & Likhitdamrongkiat, M. (2015). E-learning system to enhance cognitive skills for learners in higher education. *Proceedia-Social and Behavioral Sciences*, 174, 667–673.
- Thiyagarajan, A., Bagavandas, M., & Kosalram, K. (2019). Assessing the role of family well-being on the quality of life of Indian children with thalassemia. *BMC Pediatrics*, 19(1), 100.
- Tokur-Kesgin, M., Kocoglu-Tanyer, D., & Demir, G. (2019). A determinant for family planning attitudes and practices of men: Marriage features. *Journal of Public Health*, 27(4), 443–451.
- Tomaj, O. K., Estebsari, F., Taghavi, T., Nejad, L. B., Dastoorpoor, M., & Ghasemi, A. (2016). The effects of group play therapy on self-concept among 7 to 11 year-old children suffering from thalassemia major. *Iranian Red Crescent Medical Journal*, 18(4), 1.
- Yamane, T. (1973). Statistics: An introductory analysis.
- Zaheer, Z., Zaman, Q. U., Iqbal, M., Hameed, B., & Wazir, S. (2015). Knowledge, Attitude and practices with relevance to Thalassemia. *Journal Of Medical Sciences*, 23(2), 109–112.
- Zautra, A. J., Hall, J. S., & Murray, K. E. (2010). A new definition of health for people and communities. *Handbook of adult resilience*, *1*, 1.

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