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SOCIAL EPIDEMIOLOGICAL ANALYSIS OF RISK FACTORS AND PSYCHOSOCIAL BURDEN OF BETA THALASSEMIA MAJOR (BTM) IN PAKISTAN

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ABSTRACT: The current study aimed to find out the association of risk factors and psycho social burden of beta thalassemia major among the parents of thalassemic children; and to find out the differences of risk factors and psycho social burden of beta thalassemia major among the parents of thalassemic children based on gender and residential area. The study was based upon the quantitative research designed and samples of 932 parents of thalassemia children. The finding of the study revealed that socio economic risk factors (lack of social and financial support, sympathetic attitude of doctors and paramedics), cultural risk factors(religious restriction regarding prevention and screening of disease, strong emphasis on consanguinity) and disease related factors (lack of provision of blood and medicines, inadequate health system)are among the major risk factors associated with beta thalassemia major. The study recommends having strong emphasis on parental awareness regarding importance of counselling and screening of patients.

Keywords: Beta Thalassemia Major, Parents, Disease, Risk Factors, Psychosocial Burden

I. INTRODUCTION

In thalassemia, the body of a patient makes an anomalous form of hemoglobin, either due to reduce or absent globin subunits synthesis (Haque et al. 2015). It could be minor if one of the parents is carrier and patient is clinically either asymptomatic or have minor symptoms while contrary to this if both parents are carrier, patient develop serious form of thalassemia (Abu-Libdeh 2010). According to WHO database, globally 5% population is carrier of prevalent to hemoglobinopathies[1](Chen et al. 2015).

Different social and religious factors play an important role in thalassemia screening and prevention (El Mouzan et al. 2008). In Pakistan most of the children living with thalassemia are found by the results of socio-religious sabotages (Ali & Safiullah 2015).Since parents are reluctant to terminate pregnancy and blood screening, as a result number of thalassemia children is growing day by day. The beta thalassemia major is considered to be a vulnerable threat usually for the people belonging to lower socioeconomic backgrounds. Earlier researches (see Canatan et al. 2003) found that, parents of thalassemic children are affected by inappropriate psychological adjustment.

Parental Knowledge

This is one of important factor associated with the disease. Researches such as Broom and Adams (2016) found that not having disease related counseling and cultural traditionalism impede the effective management and prevention of beta thalassemia major across the world and especially in traditional societies.

It is estimated that around 5.6% people of the total population of Pakistan, which is 9 million of people are carrier of beta-thalassemia major. Generally, the main causes are the limited and poor health care facilities, bad financial situations of the families, large family size, low literacy rate and the lack of the

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[1] Hemoglobinopathies are inherited single-gene disorders; in most cases, they are inherited as autosomal co-dominant traits.

awareness particularly. As a result, in the coming years the number of transfusion-dependent children will be huge (Cappellini et al. 2009).

Social Factors Associated with Beta Thalassemia Major

The familial aspect of the disease globally in general and in third world particularly is determined by the various factors such as religious and cultural phenomena. Likewise, other diseases, the thalassemic patients and their family member seek support from society in general and from relatives and friends in particular (Fried et al. 2004). A rigorous social support system will also be needed from the health experts and other members of society in order to manage the social and psychological non adjustment of BTM patients. A number of studies (Ghaemi 2009 and Cappellini et al. 2009) reflect that important social support system for the thalassemic patients is their family system. Family is considered to be an important institution to share the socio psychological burden of such patients. Family usually helps such patients to reintegrate in to the mainstream society. Furthermore, to combat against the disease also needs to have social, cultural, moral and medical assistance for thalassemic children and their family system. The individuals of particular area need to have suitable basic awareness and education regarding the prevention and management of the disease.

Religious Factors of BTM

Studies on BTM such as Kawachi and Berkman (2001) revealed that the religious factor is also a major variable that determines the individual's mentality about their lives. Having clear instructions of religion about the scientific treatment of such chronic diseases, religious teachings can never be blamed for treatment of BTM on systematic and scientific standpoints. There are certain myths associated with such interpretations that the religious teachings are considered other ways and to adopt the scientific procedures to tackle such chronic illnesses.

Psycho Social Burden of BTM

Depression and anxiety are among the major factors faced by the parents and family members of children suffering from BTM. Such feelings originate from the perception that this disease is quite dangerous and may lead to permanent disability leading one to vulnerable end such as death. This results in pessimism about life of suffering children and their families too. Moreover, this negative attitude is also significantly affected by stigma generally developed about BTM (Canatan et al. 2003). Nevertheless, psychological effect of this disease greatly mars the recreational and aesthetic aspect of life of the affected children and disrupt the educational activities of children with BTM as well. Furthermore, the children with BTM also face the physical growth challenges due to abnormal growth of their hormones and face iron overloading because of over blood transfusion processes.

Social Model in Respect of Health and illness

Due to excessive critique on the bio-medical model during the contemporary era, the attention of health professionals was attracted towards integration of social side of the prevention for the disease of BTM. While having the social insights, one can find out the religious, social, and cultural practices shaping the health seeking behavior of an individual. These perceptions are composed of certain factors such as hygiene, marriage practices and other mental aspects (Cockerham 1993).

The social model explains being healthy and unhealthy based on societal interpretations. This model of health considers health as a blend of factors including sanitation, hygiene and other socio-economic factors. However, most of the scholars have conducted researches in bio medical sciences only focused the physical aspect of this illness rather than exploring the social epidemiological stance on the disease.

II. METHODOLOGY

The data collected for the study focuses the Punjab province of Pakistan and was collected from blood transfusion center (Sundas Foundation, District Gujrat). The foundation is registered with Pakistan Thalassemia Federation and owns the lists of registered thalassemic patients. A sample of 932 parents of children suffering from beta thalassemia major was selected for data collection. The tool consisted of information related to the demographic profile, while the knowledge of parents, pre and post diagnostical practices and risk factors were measured on 5-point Likert scale. The dependent variables (psychosocial burden) was also measured by using another interview schedule adopted from (Canatan et al. 2003). The data was analyzed by using SPSS (V-23) for statistical analysis.

III. RESULTS

Table 3.1
Demographic profile of the respondents

Variables		Frequency (f)	Percent (%)
Gender			
	Male	375	40.2
	Female	557	59.8
Marital Status			
	Widow	41	4.4
	Divorce	25	2.7
	Living together	866	92.9
Area of residence			
	Rural	663	71.1
	Urban	269	28.9
Father's Ethnicity			
	Punjabi	763	81.9
	Pashtun	105	11.3
	Sindhi	25	2.7
	Baloch	18	1.9
	Kashmiri	21	2.3
Mother's Ethnicity			
	Punjabi	768	82.4
	Pashtun	107	11.5
	Sindhi	18	1.9
	Baloch	18	1.9
	Kashmiri	21	2.3
Nature of Family			
	Nuclear	445	47.7
	Joint	450	48.3
	Extended	37	4.0
Occupation			
	Self-employee	315	33.8
	Private job	148	15.9
	Government job	213	22.9
	Laborers	256	27.5

Table 3.1 revealed that out of 932 respondents, 375 were male and 557 were females. The data recorded in table 3.1 also revealed that 663 respondents belonged to the rural areas of Pakistan, while 269 were selected from urban areas of the Punjab Province. Data also revealed that 763 fathers and 768 mothers were belonging to the Punjabi ethnicities while, 105 fathers and 107 mothers belonged to the Pashtun ethnicities. The study included other ethnicities Sindhi, Baloch and Kashmiri as well. The study found that majority of the respondents 445 and 450 were living in nuclear and joint families accordingly as compared to the extended family system. The data also revealed that a great number of the respondents i.e. 315 were self-employed, 213 were working in government sectors and 256 were working as laborer, however only 148 were doing private jobs.

Table 3.2
Patient's Gender Differences Regarding Knowledge, PNDs, Risk Factors and Psychosocial Burden of BTM

							95% C. I	
Variables	Gender	N	M	SD	SEM	t	Lower	Upper
Knowledge	Male	486	11.397	3.035	0.138	-1.490	-0.659	0.090
	Female	446	11.682	2.794	0.132			
PNDs	Male	486	24.599	4.747	0.215	-.233	-0.697	0.549
	Female	446	24.673	4.926	0.233			
SERF	Male	486	36.080	7.731	0.351	-2.043*	-1.997	-0.040

	Female	446	37.099	7.484	0.354			
CRF	Male	486	25.780	6.026	0.273	2.563*	0.226	1.702
	Female	446	24.816	5.452	0.258			
DRRF	Male	486	9.284	4.192	0.190	1.867	-0.024	0.982
	Female	446	8.805	3.636	0.172			
PSB	Male	486	58.837	9.410	0.427	.383	-0.993	1.475
	Female	446	58.596	9.751	0.462			

Note*p<.05, **p<0.001, Male = 486, Female = 446, PNDs=Practices of Pre/postnatal Diagnosis, SERF=Socio-economic Risk Factors, CRF=Cultural Risk Factors, DRRF=Disease Related Risk Factors, PSB=Psychosocial Burden, BTM= Beta Thalassemia Major

Table 3.2 contains the information related to certain factors of (BTM)based on gender of the patients (male, female). Data explained that the parents of thalassemic children have significant differences of socio-economic risk factors (M=36.08, SD=7.731) and cultural risk factors (M=25.780, SD=6.02) of beta thalassemia major (p<0.05). While other variables of the study including parental knowledge, practices related to BTM have no significant differences on the basis of gender of the patient (p>0.05).

Table 3.3
Residential (rural, urban) Differences Regarding Knowledge, PNDs, Risk Factors and Psychosocial Burden of BTM

Variables	Locality	N	M	SD	SEM	t	95% C. I	
							Lower	Upper
Knowledge	Rural	663	11.849	2.635	0.102	4.710**	0.638	1.551
	Urban	269	10.755	3.422	0.209			
PNDs	Rural	663	24.965	4.739	0.184	3.238*	0.451	1.844
	Urban	269	23.818	4.966	0.303			
SERF	Rural	663	36.692	7.473	0.290	.761	-0.683	1.547
	Urban	269	36.260	7.999	0.488			
CRF	Rural	663	25.813	5.756	0.224	4.170**	0.906	2.519
	Urban	269	24.100	5.650	0.344			
DRRF	Rural	663	9.163	3.998	0.155	1.346	-0.172	0.922
	Urban	269	8.788	3.792	0.231			
PSB	Rural	663	59.710	9.426	0.366	4.996**	2.077	4.771
	Urban	269	56.286	9.505	0.580			

Note*p<.05, **p<0.001, Rural = 663, Urban = 269

The respondents of present study were selected from Punjab Province. The study found (see table 3.3) a lot of differences among two communities with reference to knowledge (M=11.849, 10.755 & SD=2.635, 3.422), prenatal diagnosis (M=24.965, 23.818 & SD=4.739, 4.966) cultural risk factors (M=25.813, 24.1 & SD=5.756, 5.650) and psychosocial burden of beta thalassemia major (M=59.710, 56.286 & SD=9.426, 9.505) because (p<0.05). Parents of sick children with genetic disorder like beta thalassemia major differ in knowledge because of their residential localities. The differences of practices of prenatal diagnosis also exist on the basis of rural and urban domestic belts. Because rural people lack the access to scientific technologies for screening and diagnosis and due to lower socioeconomic status, they remained unable to adopt the pre-emptive procedures.

Table 3.4
Correlation Matrix of Knowledge, PNDs, Risk Factors and Psychosocial Burden of BTM

Variables	PSB	Knowledge	PNDs	SERF	CRF	DARF
PSB	1					
Knowledge	-.523**	1				
PNDs	.430*	.371*	1			
SERF	.638**	.461**	.621*	1		
CRF	.501**	.520*	.529**	.428**	1	
DARF	.391*	.420**	. 211*	.421**	.329	1

Note*p<.05, **p<0.001

Data recorded in table 3.4 shows significantly negative association between knowledge of the respondents' (parents of thalassemic children) about the disease and the outcome variable (psychosocial burden of BTM) r=-.523**, whereas a significant positive relationship between specific two parameters of beta thalassemia major have been found r=.430*. The data also revealed that socioeconomic risk factors r=.638**, cultural risk factors r=.501** and disease allied risk factors r=.391* were also significantly positively associated with psychosocial burden of beta thalassemia major.

IV. DISCUSSION AND CONCLUSION

A report of UNESCO in 2012 ranked Pakistan on 113 out of 120 with reference to education, clearly highlighting the educational condition in our country. This has led to the major obstacle for awareness and counseling of thalassemia. Barriers for effective communication are; language, lack of understanding of medical information, technical terminologies used by health experts and researchers, which result to create obstacles for masses to understand the cultural and social stigmatization and lack of access to the technologies. While the better communication methods involve communication with spouse, family, friends, services providers, policy makers, government agents, researchers, medical professionals, community activist, social mobilizers and advocacy experts. It is evident that countries, with technological advancement and improved communication methods enable couples to effectively manage the genetic disorders including thalassemia. A rigorous and passionate approach is required form parents and families to learn and boost their knowledge and awareness level regarding thalassemia. It is also true that providing information at a country level is a difficult task for health professionals and researchers because of social and political edifices (e.g. literacy rate, political system, patriarchy etc.). Comparing the level of awareness and the tendency toward the level of acceptance among women and the rest of society it is very challenging to effectively implement and achieve effective screening and genetic counselling, because these are the major propagating factors of thalassemia disease in Pakistan if ignored. Due to having no awareness and lack of acceptance of remediable methods of thalassemia prevention by majority of the people, the rate of this chronic disease is alarmingly growing causing Pakistani society to face challenge of tackling the issue of BTM.

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