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Social and cultural menaces of beta-thalassemia major: Narratives from Pakistan

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Abstract: The study aimed to explore social and cultural menaces of beta-thalassemia major by transcribing and analyzing the narratives and elucidations of parents of thalassemic children by using thematic analysis. Data were collected from parents at two centers of blood transfusion by mode of interview method with 12 participants. The coded accounts were thematically explained by highlighting the similarities of opinions. It has been explored that participants had a gratified attitude towards these two centers because of provision of blood and medications for their children. The extrusive categories include self-blaming, lack of education and empowerment, patriarchy, consanguinity and cultural mythologies and false religious explanations and beliefs.

Keywords: Social; Cultural; Beta thalassemia major; Pakistan

1. Introduction

Beta thalassemia is a disorder that is categorized in inherited hemoglobin issues, which are linked to a quantitative deficiency of functional beta global chains (Muncie & Campbell, 2009). Beta thalassemia is featured as, limited or defective production of the global beta chains. An imbalance in the coordination making of the subunits of hemoglobin which results in making the bone marrow produce immature red blood cells (Martino et al., 2018).

Every year approximately 50,000 children pass away due to beta-thalassemia major in low and middle-income countries, whereas, discernibly, 7% of the world's population is the carrier hemoglobin disorder (Weatherall, 2010). Five out of a hundred individuals are currently suffering from thalassemia and approximately eight million population of Pakistan is a thalassemia carrier (Muhammad, Waqas, Azhar, & Ikram, 2019). The approximate life span of thalassemia patients is ten years (Lodhi, 2003).

In a patriarchal and gender base segregated society, the women's involvement in decision making and marriage preferences are bitterly snubbed by cultural and so-called social environment (Bourque & Warren, 2010) as a result families and parents unintentionally increase the risk to propagate beta-thalassemia (Raffa, 2019). Due to lack of knowledge and awareness of premarital and genetic screening and counseling, thalassemia occurs repeatedly among the extended families and all other communities where cast, ethnic and cultural preferences are dominated for marriage (Shaw, 2009). Misperceptions about religious beliefs and practices also increase the vulnerability of thalassemia (Cappellini, Cohen, Porter, Taher, & Viprakasit, 2014) because of lack of education and empowerment, especially among the women. Limit them to raise their voices against tradition, detracted and misleading concepts related to culture and religion (Fullwiley, 2011).

The cultural implications in Pakistan involve restrictions for premarital screening, genetic and career counseling (Mirza et al., 2013). Termination of pregnancy is considered unethical and it has religious constraints allied to terminate the pregnancy with beta-thalassemia major (Ngim, Lai, & Ibrahim, 2013). Due to ethical and traditional curbs, thalassemia is treated conservatively with all its innate complications, which eventually lead to the death of the patients (Drakonaki et al., 2005). The only solution to minimize the mortality rate due to thalassemia is; by making the general public aware of the preventive measures of this chronic ailment (Hassan, Aslam, & Ikram, 2002).

The countries (Turkey, Iran. Bangladesh and Saudi Arabia), which were once known for a high level of thalassemia cases, are now using various prevention strategies, which include carriers' detection, genetic counseling and diagnostic tests of the parents. All these initiatives have almost eliminated the risk of homozygous thalassemia in new generation (Marioni et al., 2015). But in case of Pakistan, a strong resistance for all these preventive measures has been reported by researches (Ishfaq, 2015; Khan, 2018; Saeed & Piracha, 2016), which leads this disease to become a chronic ailment (Yasmeen & Hasnain, 2019).

Repeated cousin marriages have been reported as the major cause of thalassemia disease (Aqueel & Anjum, 2019). In many countries including Iran, India, Bangladesh and Pakistan where traditional believes and practices are dominant over decision

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making about marriages, genetic counseling, premarital and prenatal screenings, it is difficult to create awareness among families and alarm them about the consequences of consanguinity (Battu, Mallipatna, Elackatt, Schouten, & Webers, 2018). Among other social and cultural factors, low level of awareness and health literacy increases the risk of thalassemia (Javadzade, Mahmoodi, Hajivandi, Ghaedi, & Reisi, 2019). In many traditional societies, Pakistani couples and families also believe in cultural practices and preferred cousin marriages; as a result, the higher rate of thalassemia (11% of the population is a carrier of thalassemia) have been reported in-country (Tanveer, Masud, & Butt, 2018).

Lack of social support from the society, relatives and friends; creates a massive social burden, emotional disorder and lack of self-efficacy among parents of thalassemic children (Pouraboli, Abedi, Abbaszadeh, & Kazemi, 2017), which ultimately affects the social wellbeing and quality of life of parents and children (Mikael & Al-Allawi, 2018). It becomes challenging for the parents to bear the psychological and emotional pain due to the physical abnormalities of their children due to the beta-thalassemia major (Shahraki-vahed, Firouzkouhi, Abdollahimohammad, & Ghalgaie, 2017).

Insufficient healthcare facilities, exorbitant medical treatments and financial constraints are the major obstacles for effective management of thalassemia (Punaglom, Kongvattananon, & Somprasert, 2019). As majority of the vulnerable families and communities live in rural areas of Pakistan with limited financial resources and having low level of education remain unaware regarding effective management and prevention of beta-thalassemia major (Ghafoor, 2016) and cannot be screened by the government, non-governmental organizations and blood donation organizations (Ebrahim et al., 2019).

2. Theoretical and methodological framework

The theoretical facets of this study are borrowed from the interpretive sociology of health and illness and social model of health, which view health as a socially constructed portent, unlike biomedical model of health and illness (Farre & Rapley, 2017). The social construction of health comprehends the interpretive approaches of sociology of health and illness (Yazdannik, Yousefy, & Mohammadi, 2017). The subject incorporates the nature of social and cultural aspects as the core elements for production, consumption and distribution of health (Abel, 2007). The cultural vindications have seen to be very potent part in understanding, explanation and for the treatment of health, especially in developing countries (Zarcadoolas, Pleasant, & Greer, 2005) and in traditional societies (Maher, 1999). Unerringly, the present study incorporates the ideas of Verstehen, introduced by German philosophers - specifically used by Max Weber (Eldridge, 1971) and George Simmel (Helle, 2012) in the field of sociology.

3. Study procedures

The study was conducted at two different centers of blood transfusion; Sundas Foundation Gujrat† and Jamila Sultana Foundation Rawalpindi‡. Twelve parents were equally selected from centers, three males and three females from each in March 2019. All included respondents were selected on the basis of a define inclusion criteria, particularly developed for the study; those parents whose child must be the patient of beta-thalassemia major, either gender, having a diverse socio-economic background and educational level. All the parents who were included in the process of data collection were briefed about the nature and purpose of the study and a consent form was signed by them (participant) to ensure the ethical standards of academic research. Data was collected by using a semi-structured interview schedule when parents came for blood transfusion of their children. Every interview took 45-50 minutes and narratives were recorded with the endorsement and inclination of parents. The collected data was transcribed and information was sent for thematic analysis. The imaginary names were given to the participants to quote their responses and narratives. The process includes the following stages:

1. Detail reading each transcribed interview
2. Finding out the similarities and differences of narratives and developing codes
3. Delimiting and merging common aspects for developing themes
4. Discussing major themes

4. Results

The results of this study based on the narratives and opinions of participants regarding sickness of their children.

4.1. Classification of the participants

The focus group discussions (FGDs) were conducted at Jamila Sultana Foundation, Sundas Foundation-Gujrat and Fatimid Foundation-Multan, including 12 participants (parents of thalassemic children) in each focus group session. In each session, other than representatives of foundations, parents were ranging from illiterate to holding university education. Their professions and natures of jobs were house wife, labourer, small

† The Sundas Foundation is the pioneer of the voluntary blood transfusion service and is registered as a member of Thalassemia International Federation (T.I.F.) and World Hemophilia Federation.

‡ JSF is affiliated with International thalassemia Federation and registered with Thalassemia federation of Pakistan

entrepreneurs, private jobs and government employees and they had a diverse ethnic background; eight were Punjabi, five were Pashtun and three were Kashmiri and two form Sindhi ethnic group, living in the Punjab Province.

4.2. Personal feelings of the participants

With a very warm and gratified attitude, almost all parents appreciated the contribution and aid provided by the thalassemia's foundations. They were much obliged by the timely and proactive response of these centers for the provision of blood and chelation therapies. They were of the view that these organizations are helping us beyond their expectations:

"The organization is the only hope for survival of our kid- I was hopeless but this organization exhibited a beam of life for my child" (participant A).

The centers were managing blood through their camps, door to door collections, providing seasonal clothes to the poor families and arranging recreational trips for thalassemic children.

"I was unable to manage blood because my family members, relatives and friends stop their social, moral and financial support, then I came to the organization and I am receiving blood and medicines for my kid, free of cost" (participant B).

4.3. Self-blaming

The results of study revealed that the parents blindly followed social and cultural practices, generally followed in health, marriages and for family planning due to lack of knowledge and awareness. They were of the view that if they considered the aftereffects of cousin marriages and denial of screening, they could be able to save the life of their kid.

"I never thought that due to consanguinity, my child could have thalassemia" (participant C).

These parents realized the importance of blood screening, genetic counseling, prenatal and post-natal precautions after their children became thalassemic and they said that everyone should go for these precautions to save the lives of future children.

"I ignored the importance of screening and counseling, which resulted my child to suffer the chronic disease" (participant D).

4.4. Consanguinity and cultural mythologies

Some of the parents were living in joint and extended families and they all had cousin marriages. Due to endogamy, cast, ethnic preferences and traditional normative practices, these participants opted cousin marriages.

"In our family we cannot wish to marry out of cast" (participant A).

Another participant said that

"My parents did the same as I because we are not allowed to marry out of family" (participant E).

Their marriage decisions hardly include their personal choices and due to repeated cousin marriages, their children were suffering from this chronic genetic disorder.

"When my child born with thalassemia and I came to know that this happens due to cousin marriages, so I requested my family to stop this tradition of intentional killing of children" (participant F).

4.5. Religious fallacies

False concept narrated by religious preachers and local people misguided parents for the identification and treatment of thalassemia. Participant believed that it is the will of God that our children had this chronic disease otherwise religion does not restrain couple to go for abortion-but within a particular time of fetus maturity,

"Although this is a disfavoured and unlawful act but Islam allow Muslims to abort, in case of having fear of death of mother or child within 120 days of fetus maturity" (participant A).

This is evident that due to delayed identification of disease, it becomes chronic and allied many other severe health problems such as cardiac, diabetes, anemia, insomnia, hemophilia, body pain, mental stress and other physical issues. The reasons for delayed identification were reported by the parents that;

"I initially went to the spiritual healers and religious celebrants for the treatment of thalassemia because I was unaware of its cause and consequences, later I came to know that there is no other way but blood transfusion to battle this disease" (participant B).

4.6. Patriarchy

Due to male dominancy in traditional societies, women are usually not allowed to take part in decision making, even related to their personal lives (i.e. education, career choices, marriage and family planning).

"I was not asked before marriage, either I want to marry or not" (participant E).

Pre-marital and post-natal screenings are compulsory for career detection, but male

dominancy does not allow women to go for it especially for premarital screening and they even deny for themselves by considering a humiliation of their self-esteem.

"I never recognized the importance of screening which resulted the pervasiveness of chronic disease" (participant F).

The study found that along with female respondents, the male members were also viewed patriarchal structure as a hinderance for carrier detection, genetic counselling and adaptation of preventive measures (birth control and termination of pregnancy).

5. Discussion

Due to lack of knowledge and awareness of beta-thalassemia major, this genetic disorder becomes chronic illness among Pakistani people (Manzoor & Zakar, 2019). It is evident that low level of education in all high rated countries (India, Bangladesh, Iran, Saudi Arabia, Jordon and Pakistan), trigger thalassemia (Haq et al., 2017; Hossain et al., 2016; Mashayekhi, Jozdani, Chamak, & Mehni, 2016; Olwi, Merdad, & Ramadan, 2018; Sarvestani, Hasanifar, & Bagheri, 2019). The possibility to overcome this biological disorder is, to create high level of awareness among the families about genetic counseling and screening (Katapodi et al., 2018) and empowering parents to choose the precautionary measures to avoid propagation of beta-thalassemia major (Bender, 2017). Due to denial and unawareness about genetic counseling and screening, most of the parents blame themselves for becoming the cause of thalassemia occurrence among their children. Their pessimism creates many psychological abnormalities e.g. anxiety (Khamoushi et al., 2015), depression (Khoury et al., 2012), mental stress (Messina et al., 2008) and social problems e.g. social isolation (Mashayekhi et al., 2016), stigmatization (Cao & Kan, 2013), week social interaction (Gharaibeh, Amarneh, & Zamzam, 2009) and denial of acceptance (Ali, Sabih, Jehan, Anwar, & Javed, 2012), for their children and for themselves.

Communities with traditional believes and practices for heath management, have a greater chances of propagation of thalassemia (Hamamy, 2012) because of angelic emphasize on consanguinity, endogamy, cast and ethnic preferences for marriages. Meanwhile, the falsifications- attached with religion unwise people to go for scientific treatment of beta-thalassemia major. In all patriarchal and traditional societies generally and in Pakistan particularly, the termination of pregnancy due to beta-thalassemia major is an unlawful act (Moghadam, 1992), the interpreters support such kind of argument with false religious beliefs, because the religious aspects of abortion in Pakistan (through Islam) are very clear, within the particular period of time i.e., 120 days (Jafri et al., 2012).

6. Final consideration

The chronic pervasiveness of beta-thalassemia major is howbeit a genetic abnormality; due to deficiency of beta protein in human blood but it has some elemental social and cultural menaces. In this study the cultural and social aspects were explored by participant's narratives, using thematic analysis. Participants emphasized on the importance of genetic counseling and pre/post-natal screening because they experienced and victimized their child by neglecting or being unaware these effective management measures. Blindly following the traditional and supernatural practices for the treatment and management of beta-thalassemia major, worsen the quality of life and wellbeing of whole family of a sick child. Male dominancy and consanguinity do not allow women and young couples to go for carrier detection and as a result the infant experienced a deadly disease.

Although the results of this study are based on lived experiences and narratives of the parents of thalassemic children and due to diverse social and cultural settings across the world, these results cannot be generalized to the overall population.

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