

## **A Qualitative Analysis of Health among Microcephalies (Shah Daula Community): Narratives from Gujrat, Punjab Pakistan**

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### **Abstract**

The Shah Daula community in Gujrat, Pakistan, has been linked to religious and humanitarian endeavors, especially providing care for youngsters suffering from mental illnesses and microcephaly. The study aimed to examine the social, physical, and sexual health issues of Micro-cephalic people (Shah Daula community). The data was gathered by using the qualitative approach. The interviews were conducted with the attendants of the population of the Shah Daula community as they are the caretakers of the Micro-cephalic patient's health issues from Gujrat and Rawalpindi. The sample was selected by convenience sampling technique and fifteen respondents were selected for interviews. Moreover, the study used thematic analysis for the interpretation of the data. The results showed that the Shah Daula community's health issues are based on their belief system. Because of these belief systems, their social, physical, and sexual health issues were neglected. No health services were provided to this community regarding their social, physical, and sexual health needs. They were stigmatized that they had no disease but they were the gift of GOD (*Murad* and *manat*). The findings suggest that there is a need to aware

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people of the issue of Micro-cephalic and that one should not stick to this health issue with some traditional beliefs and should be provided proper health services according to their needs.

**Keywords:** *Shah Daula Community, Microcephaly, Belief, Health Issues.*

## **Introduction**

The Shah Daula community in Gujrat, Pakistan, has been linked to religious and humanitarian endeavors, especially providing care for youngsters suffering from mental illnesses and microcephaly. However, over time, this admirable objective was misunderstood, which resulted in claims of child abuse and exploitation in the neighborhood. Originally, Hazrat Kabiruddin Shah Daula Daryaie Ganj Bakhsh Ramatullah Ellai's shrine was well-known for providing care for crippled children. However, these youngsters were brutally trafficked by their ostensible followers, who exploited and mistreated them as beggars (Mumtaz, 2023).

The problems facing the community are not limited to religious and humanitarian endeavors; they also include more general health concerns (Brousard et al., 2019). The notion of community health concerns, as expounded in several scholarly sources, underscores the significance of tackling environmental variables, public health measures, and social elements to foster community well-being. Key elements of community health that interact with the social fabric of the Shah Daula community and its surrounds are issues like poverty, sanitation, disease control, and access to healthcare services (Asaduzman et al., 2021).

The disease that causes the short size of the brain is known as microcephaly. In Pakistan, about 4 percent of the population is reported to have microcephaly (Rasool et al., 2020). This disease is caused by many reasons such as genetic disorders, use of drugs and alcohol, and many other

viruses could be a reason as well which could affect a fetus and damage the brain which is then reduced from its original size (Papova et al., 2023).

In Pakistan, it is more than 300 years since these microcephalic patients have been associated with the Shah Daulah's shrine in the city of Gujrat in the province of Punjab. The Shah Daulah community in Gujrat, Pakistan has historically dealt with problems relating to the exploitation of disabled children, especially those suffering from microcephaly, by some of the so-called adherents of the Muslim saint Shah Daulah (Syed, 2024). These children, known as "Chuhas" or "Mice of Shah Daulah", were forced to beg and perform for religious mendicants, often suffering abuse (Rahat et al., 2022).

### **Background of Shah Daulahs living in Gujrat:**

In the 1960s, the Auqaf Department of Punjab took custody of the shrine of Shah Daulah to address these problems (Anjum, 2021). However, the underlying social and economic factors that led to the exploitation of these vulnerable children likely persist in the community. Poverty, lack of access to education and healthcare, and social stigma surrounding disabilities can contribute to the marginalization of individuals with conditions like microcephaly (Haroon, 2021).

Peershad Doula Darbar is the most famous shrine in Gujrat city. People perceived that the couple who have no children get there and pray for the children. After that, the woman got a child which she and her husband had to give to the shrine (Rahat et al., 2022). These children are rats of that shrine. After that those children are used for begging. Some perceptions are also that an iron cap or helmet is used and set on the heads of newborns due to which they become the rats of shah doula and then involved in begging and

slavery. This is because of the cap that their brain is unable to grow as normal and reduce in size (Usman, 2021)

Hundreds of women came to that shrine and donated their first child whether healthy or non-healthy, to them and they became Shah doula rats because they perceived that they were the result of that 'manat' or prayer they had on the shrine (Rivera, 2021). We can see that in setting this value and ritual for microcephalic patients of Pakistan, people set Islam as a major component of it and people follow them blindly for the grace of God and His blessings which exploit those children in many ways (Mumtaz, 2023).

### **Research Objectives**

The following were the objectives of this research:

- To document the health issues of the Shsh Daula Community.
- To find out the differences in health-related issues of the Shah Daula Community and other community members.
- To find out available health services for the Shah Daula Community.

### **Research Questions**

The current study was aimed to answer the following questions:

- What health issues do the people of the Shah Daula Community face?
- How does there exist any difference between the health issues of the Daula Shah Community and other members of the community?
- What kind of health services have been provided to the Shah Daula Community?

### **Review of Literature**

A study conducted (Ghilzai & Ijaz, 2016) described that microcephaly is a medical disorder characterized by a baby's head being smaller than expected. This condition arises when a baby's brain either stops growing or

fails to develop fully, resulting in a tiny head size. Microcephaly may manifest alone or in conjunction with other congenital abnormalities. Although the individuals with this illness are not particularly similar to rats, their eyes and foreheads represent their dehumanizing moniker. Here in our community, these kids are referred to as rats. Usually, one can find them at saints' shrines, like Shah Daula in Pakistan.

A historical study (Nadeem & Afzal, 2022) explored that Shah Daula lived under the rule of several Mughal emperors, including Aurangzeb, Jehangir, Akbar, and Shah Jahan. When Shah Daula passed away, he was 95 years old. He was a kindhearted person who respected everyone, regardless of caste. In addition to teaching and counseling, he engaged in philanthropic activities. Chattar Singh, the Hindu Raja, was one of his pupils. He treated every animal with great kindness, even the stupid ones. He was very kind to deer and birds. He constructed numerous structures close to Chenab. Given how frequently floods occurred during the period, this prevented countless deaths. Many miracles have been connected to him.

In the global context (Amitel, 2017) explained that microcephaly patients who are indistinguishable from Gujrat Chuhas are found all over the world. Microcephalic refers to a skull that is less than four or five inches in circumference than average. For this reason, a 17-inch skull is referred to as microcephalic in Europe. The size of the human face and cranium distinguishes him from lesser creatures. Any physical defect that causes a person's face to enlarge (such as prognathism) or that reduces the size of their cranium gives them the look of an animal (Fernandes, 2015). Because the impacted and normal skulls differ in size and shape, microcephaly exacerbates the effects of animalism.

Researches regarding religious extremism and the government which is necessary to protect our Islam, are less in number. There is a concept of faith healers, which is quite famous in Pakistan as well. The belief in healing the disease or sick through some religious means is famous throughout the entire world. However, the most famous and popular region in this concept is South Asia (Charan et al., 2020).

In the Pakistani context (Rahat et al., 2022) explored that Gujrat, a city in Pakistani Punjab, treats the microcephaly problem as a taboo aberration. In the taboo practice of producing Shah Daula rats, newborns are mistreated and have an iron helmet put on their heads to prevent them from developing normally. Their physical development is controlled, and they are unable to live typical lives. This ritual abuse, which is still carried out in Pakistan under the cover of religion, has degraded humanity for years and is done solely for the sake of begging.

In a study (Charan et al., 2020) explained different things about it. Such as some differences between Europe, South Asia, and North America. He also explains that Bangladesh and India along with Pakistan are the same popular for their extreme superstition. According to his explanation, the things attached to Chua's of shah Daula such as the concept of blessings and curses are all myths. There are many explanations in the previous research about microcephalic disease. Such as microcephaly could be caused by genetic, metabolic, and different infectious diseases. It is defined as it is a short-head disease in the fetus. She also identifies the signs and symptoms of the disease (Ducker et al., 2021).

A study conducted on the life of Shah Daula (Reshamwala, 2021) explored that Peer Shah Daula had a gentle disposition and loved both people and animals. As a result of his compassionate actions, he enjoyed dressing

mentally ill children in hats to enhance their appearance. According to the accounts, the custom remains important until today. Shah Daula thought the rat child was a unique human being with a disability. The story also explains how Shah Daula, the saint, used to cap handicapped children, a custom that has since become frowned upon (Anand, 2020). The research claims that iron rods wrapped around the heads of the healthy newborns at the shrine later resulted in cranial deformities.

The researchers are also given evidence that there is a shrine in Gujrat, Pakistan which had a Saint in old times who was given much respect by the people of Punjab. Women who did not have any children came there, prayed there, and gave their first child to the shrine (Qadar & Waheed, 2024). In Pakistan, there are many genetic micro-cephalic families. Research also mentioned that there are 31 from 35 families who have this genetic disease (Ding et al., 2021).

From all the above literature review, it can be seen that most of the studies have seen this problem genetically and biologically. None of the studies focused on their health issues concerning gender as well as their social and sexual life. They focused only on the biological dimensions of microcephaly but ignored their social and sexual health problem with references to their gender.

### **Theoretical Framework**

Arthur Michael Kleinman (born March 11, 1941) is an American psychiatrist and a professor of medical anthropology and cross-cultural psychiatry at Harvard University. He is well known for his work on mental illness in Chinese culture.

Kleinman has contributed to anthropological and medical understanding of culture-bound syndromes, particularly in Chinese and East Asian cultures. In 1997 Kleinmann and Lock gave a theory on “social

suffering”. This provides a framework that holds potentially useful implications for global health (Jacobsen et al., 2023).

First, socioeconomic and sociopolitical forces are as important as the other factors that cause any disease, with the structural violence of poverty that creates the situation for the disease tuberculosis.

Second, those social institutions are also important.

Third, social suffering portrays the idea that the pain and suffering of an individual do not harm the individual only but also their families and social networks.

Finally, the theory of social suffering explains the difference between what is a health problem and what is a social problem by explaining different situations of both social and health policies. For example, social problems may include urban slum areas where poverty, violence, broken families, suicide, depression, and stress disorders are high. This theory is best linked with the issue of Microcephaly patients in Pakistan.

### **Research Methodology**

The research design of this study was qualitative. The data was collected through observation, informal discussions, in-depth interviews, focused group discussions, and key informant interviews. The day-to-day life of persons with microcephaly and their interaction with the local population was observed. During informal discussions, while developing rapport, the life patterns of the targeted population were discussed. For this study non-probability sampling technique was used to identify the sample population. The people with microcephaly, are known as ‘Rats of Shah Daula’ in Pakistan. So, through a convenient sampling technique a sample of 15 ‘Rats of Shah Daula’ were selected. There was no gender difference in the selection of



respondents but the available sample set comprised 11 males and 4 females from the shrine of Shah Daula, Gujrat.

During this qualitative study, the method for data collection was an in-depth interview. This method was used to get in-depth information to answer the research questions. A semi-structured interview guide was developed and used as an instrument for data collection. There were a total of 20 open-ended questions in the semistructured interview guide. Through this tool, the researcher had the choice of probing and asking the next question in a given context and situation.

### **Ethical Considerations:**

The data was collected after getting consent from the attendants of the shrine. They were assured that the information and identity, they provide will remain confidential and anonymous. The purpose of the study was made clear to the respondents. The queries regarding the nature of the research were also answered to satisfy the respondents. The interviews were conducted with the people who were willing to talk about the issue. It was also conveyed that in case of any discomfort, they can withdraw from this study at any time. Hence, the data was collected by keeping in mind all the ethical considerations of research.

### **Data Analysis**

The researcher coded data from interviews and made themes of the data for thematic analysis of data. Thematic analysis is a qualitative research method used to identify, analyze, and report patterns (themes) within data. It involves systematically coding and interpreting data to uncover meaningful themes or patterns that provide insight into the research. The thematic analysis of data is as follows:

### **Shah Daula and their daily life activities**

According to the interview answers, it is revealed that Shah Daula individuals cannot do their daily life activities by themselves. They need a full-time attendant who does their daily life activities for them such as eating a meal, drinking water, and hygienic needs all are done by the attendants to them. Such as one respondent said,

“We do not be able to do their work. Like we do their work, we give them a meal on time. We take care of them.”

Another answer shows that attendants are needed for their daily life activities as,

“We do not do their daily work like eating or going to the washroom. If we see the food they will eat it. Otherwise, they would not ask for it. So we have to give them food on time.”

This answer shows that Shah Daula individual cannot do their daily life activities.

According to the dialogues it is also revealed that the Shah Daula individuals need a full-time attendant with them to take care of them and for their daily life activities.

One of the respondents said,

“Yes, we need an attendant every time. Who has the responsibility to take care of them and watch them that we don’t eat something poisoned”.

One other answer shows,

“I am with her every time. If I let her alone, she will be lost”.

So these answers show that an attendant must be with them to take care of them and it was understood that they do not have an understanding ability so they need a person to look after them every time.

## **Physical Activities**

It is also revealed that Shah Daula individuals can listen properly. They can also walk properly if they don't have any disability which cannot let them walk. Otherwise, they can walk. But all of them cannot speak and not be able to inform others about their condition to others. As in many answers, it is stated that they can't speak.

In one answer it was stated by a respondent as,

“I can walk properly and do not need any kind of support,” and he also added in the next answer, “I can listen but can't speak and understand things.”

So it is revealed that they cannot speak and understand the things happening in their surroundings.

## **Female Shah Daula and Reproductive Health**

Female Shah Daula's reproductive health is not clear from the respondent's answers as they were not aware of the reproductive cycle of female Shah Daula. So from the answer, it was not found whether they got their reproductive cycle or not.

## **Shah Daula Rats and God's Gift**

It is also revealed that Shah Daula individuals are the gift that has been got by the people after many prayers (muraadein and manatein).

Many answers revealed that they are a gift one respondent said,

“We do not have any disease. They are the gift from GOD we are signified (ye muradon k hty hain).”

## **Shah Daula Rats and Disease of Microcephaly**

They also came to know that as they are the gifts of “Shah Daula” they do not have any kind of disease or health problem.

One of the respondents said,

“We are signified. They come after many prayers (muraadein) so we do not get any health problems.”

One other respondent said,

“We do not have the disease they the gift of GOD given to us by Shah Daula peer.”

So from these answers, it is come to know that as they are a gift,s so they never have any kind of health disease or problems.

### **Understanding the health conditions**

It is also revealed that the attendants of Shah Daula have to understand their condition by themselves. Because Shah Daula individuals cannot speak and cannot be able to tell others about their conditions attendants have to understand them and take care of them.

Many answers revealed that attendants by themselves have to understand their conditions and problems.

Such as one of the respondents said,

“The person who looks after them here (shrine) understands their condition of health and other conditions as well by themselves.”

One other respondent said,

“We cannot speak so we have to understand them by ourselves.”

From the answers, it is also revealed that the attendants found no difficulty in understanding their conditions or problems as they live with them so they know them and understand them easily. One of the respondents stated,

“We do not face any kind of difficulty in understanding their condition as we live with them so we can understand them easily.”

So the respondents know these individuals very closely.

### **Shah Daula and their Angriiness Level**

It is also revealed that angriness level is also present in these individuals which shows their emotional health. According to the answers of the respondents, it has become known that on teasing these individuals sulked. And in this condition, they sometimes lose control over themselves and throw things away.

One of the respondents stated,

“If you tease her, she sulks. She throws the things away and does not talk to you.”

According to the answer, we also come to know that these individuals sometimes get convulsions in which they also lose control over themselves. Such as one answer stated,

“We have ordinary problems regarding health. Sometimes he gets convulsions and then he loses control over himself and throws things away.”

So it is revealed that the level of anger in these individuals is quite high.

### **Shah Daula and their diet**

From the answers of respondents, it is come to know that there is no special kind of food used to give these individuals according to their health condition. They eat whatever food is available to them.

### **Health services for Shah Daula at the shrine**

According to the answers, it is revealed that these individuals are mostly provided by all health services inside the shrine. The respondents did not tell us about health problems like fever, flu, pains, etc but according to their answers it is come to know that all health services are provided inside the shrine, but they might be taken to the hospital if in future they get some serious

injuries. Such as one respondent said, “We provide them everything here (in a shrine).”

One other answer revealed that if they got a severe wound or injury they inform the other people who work there to decide whether they will treat inside or get a visit to the doctor. During an in-depth interview, one of the respondents took a sob and said,

“If we have any severe wound or bleeding then we inform the committee people to decide whether we will treat inside or take to the hospital. And mostly we treat here.”

Some respondents revealed that they do not get any wounds or serious diseases as they are the gifts but if they get any severe injury in the future so might be taken out of the shrine.

One respondent stated,

“If any of them got any severe wound or accident we might take them out of here (shrine) but these are the gifts of GOD they do not get any problem.”

So, many health services given inside the shrine were not taken out of the shrine and were not visited by a doctor.

### **Shah Daula and their Differences from Other People**

According to the answers, it is revealed that the only difference according to the respondents or attendants of Shah Daula individuals and ordinary individuals is that they have small heads and can't speak like a normal person. It is also revealed that this is normal for them as they consider them as a gift of GOD.

Such as one respondent said,

“They have no disease. They just have a small head by an ordinary person but this is the gift of GOD.”

One other respondent stated,

“Yes, they are physically different from an ordinary person as you can see they have small heads and they cannot speak, think, and understand things as we do.”

The other respondents stated that “the health issues there are the same as ordinary people but the only difference is that they cannot speak.” So, these answers revealed that according to the attendants and respondents, the only health problem that the Shah Daula individuals have is they can’t speak.

### **Gender, Shah Daula, and Health Problems**

According to the answers of respondents, it is known that both Shah Daula male and Shah Daula female have the same health problem and it was that they both cannot speak and have small heads. Otherwise, the respondents did not talk about the internal health problems, seasonal health problems, social health problems, and sexual health problems of Shah Daula male and female individuals.

### **Discussion**

Health is the most important part of human life because all things depend on it if they are not healthy they can’t do anything they can’t perform their daily life activities. Nowadays people neglect their health they don’t eat a proper diet not involved in other physical activities not follow doctor's prescriptions and many other things like that and these things affect their health very badly. In this thing not only people's neglection play a role but many other things that involved in it like belief systems either they are related to religion or culture, illiteracy among people, poverty, lack of awareness about health, health service, economic and political issues etc. social suffering theory also talk about these things in this theory Lock M and Kleinmand said that health

problem and social problem same they also talk about these things that they play a very important role in the health sector.

Many communities are affected because of these things their health system is affected. We selected one of the most important communities for our research that are Shah Daula's. In Pakistan, many rituals are performed in the name of religion. The people with microcephaly, are also associated to be the religious ones. In the city of Gujrat, Pakistan, there is a very large number of people having microcephaly may be because of certain biological reasons or customary traditions, but people living there or in other areas of Pakistan, believed them to be the 'Chua's of Daula Shah' or rats or mice and they consider them as holy men. It is believed that, by the prayer of the rats of Daula Shah, the infertile women get conceived and their first child will be as same in features as the rats of Daula Shah, and these children ought to donate to the shrine of Daula Shah.

We found out this thing in our interviews that people continuously responded that these people have no other disease they like that because they are the God gifted people not single person said that they have microcephaly diseases and no none of them knows that there is any disease like that and these people pass through this thing and this thing indicates us that how much they strongly believe in other religious beliefs. The social suffering theory said the same thing that social beliefs play a very important role because we build over beliefs on it and this thing we see in our research.

The social suffering theory highlights two things poverty and economic poverty increase day by day because we have fewer economic resources and less number of job opportunities because of this people do not have much money and because of this thing illiteracy increases day by day and people are unaware about these and follow the traditions and because of this the beliefs



are more strong and because of this beliefs are more strong as compared to medication. So through over findings, we found out that this is a disease that is based on our religious and social beliefs. And just because of this people use them as beggars. And not properly give them treatment or medication.

## **Conclusion**

In Pakistan, many rituals are performed in the name of religion. The people with microcephaly, are also associated to be the religious ones. In the city of Gujrat, Pakistan, there is a very large number of people having microcephaly may be because of certain biological reasons or customary traditions, but people living there or in other areas of Pakistan, believed them to be the 'Chua's of Daula Shah' or rats or mice and they consider them as holy men. It is believed that, by the prayer of the rats of Daula Shah, the infertile women get conceived and their first child will be as same in features as the rats of Daula Shah, and these children ought to donate to the shrine of Daula Shah. In this study, we focus on exploring the health issues of the microcephaly people of the Shah Daula community, analyze the difference between the other health issues of microcephaly people and normal people, and explore the health services provided to the microcephaly people of the Shah Daula community.

Our research findings show that this thing is based on the belief system and because of this thing their social, sexual, and physical health needs are affected no one considers them microcephaly patients. They have no proper health services people only attached a stigma to them that the short-headed people are Shah Daula and these people are only allowed to live in the shrine. The most important thing shown in our result is that women's health is neglected no proper health service system for them. So, there is a need to aware people of the issue of microcephaly, is one should not stick this health issue with some traditional beliefs.

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