

Well-Being Issues of Persons with Mental Illness: Some Case Studies in Mizoram

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INTRODUCTION

The word ‘disability’ is a broad term which makes its definition rather complicated (Gutterman, 2023). ‘There is no single definition of disability’ (Mitra, 2006). Defining disability is complicated as it is ‘complex, dynamic, multidimensional and contested’ (World Health Organization, 2011). ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (UNCRPD, 2006).

As per the RPWD Act 2016, there are 21 types of disabilities which include blindness, low-vision, leprosy cured persons, hearing impairment, locomotor disability, dwarfism, intellectual disability, mental illness, autism spectrum disorder, cerebral palsy, muscular dystrophy, chronic neurological conditions, specific learning disabilities, multiple sclerosis, speech and language disability, thalassemia, haemophilia, sickle cell disease, multiple disabilities including deaf-blindness, acid attack victims and Parkinson’s disease. Thus, mental disorder or mental health condition is one among the various types of disabilities, which is a matter of grave concern now (Balakrishnan et al., 2019). The major contributors of the increased global burden of disease is disability associated with mental illness (Chaudhury et.al., 2006).

Shareef & Shafaat (2021) have defined mental disability as any psychic health disorder which is related to a person’s decision making processes, mind cognition and problem solving ability. It is a disorder which is characterized by a clinically significant disturbance which has a tremendous effect on an individual’s cognition, emotional regulation, or behaviour and it is most often associated with distress or conditions which disrupts the important functioning areas of an individual (Stein et al., 2021). In the field of sociology, the issues associated with mental illness causes ‘dysfunctions’ in society (Merton & merton, 1968).

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The dysfunctions associated with mental disorders are usually 'harmful dysfunctions' (Wakefield, 1992). Among all the several types of disabilities, mentally ill and intellectual disabilities make up a sizeable chunk (Shareef & Shafaat, 2021). A study conducted by World Health Organisation (2022) has revealed that out of every 8 persons, one person or around 970 million people tend to have issues with mental health conditions or mental disorder all around the world. Disability associated with mental illness is an old issue and a new challenge today requiring not only meaningful explanation but also actionable recommendations (Tiwari et al., 2012). The issues faced by mentally ill and intellectual disabilities do not stop at the family level but extends much beyond to the society as well (Meghrajani et al., 2023). The amount of socio-psychological challenges and issues faced by people suffering from mental illnesses is extensive and immeasurable. This paper interrogates mental health issues of persons with disabilities with some two limited case studies.

LITERATURE REVIEW

A study published by Brennan et.al.(2018) has revealed various work life challenges faced by families having children with disabilities. The first and foremost is the challenge of giving exceptional care responsibilities, which is not similar to the typical caregiving responsibilities given to other normal children (Tayob & Risenga, 2022). It is found that 13.5% of parents spend 11 or more hours per week caring for children with special health care needs. It is also on-going parental responsibilities which may last throughout childhood into young adulthood or beyond, and more frequent and crisis-driven care needs which can have a long lasting effect on their mental health. Besides the problem faced at family level, various problems are directed towards them by society such as exclusion from various community places (Sammon & Burchell, 2018).

Community integration problem arises when children with certain disabilities are asked to leave certain community activities such as child care, church, sports activities and so on (Jivanjee et.al.2008). In these sad situations, parents are also requested to leave as well which hinder their chances of improving their social skills and leave them feeling lonely, affecting the mental health of not only the children but also the parents as well (Pledger, 2003; Salzer, 2006). This definitely affects the parents' quality of life to a greater extent and added more stress because these activities somehow tends to serve as the opportunities for them to take part in

community integration. It also limits opportunities to enjoy fully integrated lives in their communities. Apart from exclusion, another discrimination faced by them comes in the form of stigma and stereotyping problem (Corrigan & Watson, 2002).

Link&Phelan (2001) said that people with disabilities experience prejudice, stereotyping, and discrimination that affect each and every area of their lives. As such, it creates physical and social isolation and also limits opportunities to live fully integrated lives in their own respective community (Venkatesh et al., 2015). The family members also faced the same stigma at the same time as their disabled family member as it disqualified them from full and effective participation in society (Fitzpatrick, 2008).

At the theoretical level, there are some models and theoretical perspectives available such as the moral and religious model, the medical model and the social model to put mental illness based disability into perspective. The moral and religious model of disability, stated by Henderson & Bryan (2011), have stressed the fact that when parents or their grandparents commit sins which go against the law of God, their deeds will not be erased and will be punished in the form of disability to their children or even their grandchildren. This punishment is meted out by the all-powerful entity, God. Beaudry (2016) had stated that in the medical model of disability, management of the disability is aimed at a "cure," or the individual's adjustment and change that would lead to an "almost-cure". In this model of disability, medical experts are the ones who come up with defining the terms as well as offering solutions to the problems. The Social Model stated that disability stems from the oppression and exclusion meted out by society which is inflicted upon people with disabilities. The model also stated that disability is not necessarily the impairment that exists within an individual (Beaudry, 2016).

METHODS

The study uses qualitative research approach and case study method was adopted for this study. The case study method allows a multi-faceted and in-depth analysis and explorations of complex mental illness issues experienced by the participants in their real-life settings (Crowe et al., 2011). The two participants for the case study were selected randomly from the Unique Disability Identity (UDID) card holder list obtained from the Social Welfare & Tribal Affairs Department, Government of Mizoram.

The list of UDID card holder list contains different persons with disabilities in Mizoram in which people with mental illness are only in a small number. Hence, after a careful study of their background and their socio-economic profiles, two people with mental illness were selected from Aizawl, the district capital of Mizoram and one woman with mental illness was selected from Lunglei, the second biggest district in Mizoram. Ethical approval for the study is obtained from The Human Ethics Committee of Mizoram University, Mizoram, India (MZU/HEC/2024/004). Through the following case studies, the implications of the theoretical perspectives require to be worked out and the well-being issues faced by these participants are then analysed through through the in-depth study. The participants and their family members gave their consent to be included in the study and they were studied for a period of six months. The real names of the participants as well as their family members and their localities were concealed and were all given pseudonyms for this particular study in order to maintain anonymity.

RESEARCH GAP

The study of mental illness has often been conducted from a medical and psychological point of view. A majority of this study has been a quantitative study and a focus among tribal people is less. Besides, the study of well-being issues associated with mental illness from a sociological point of view through case study method is very limited.

RESULTS

The key findings through case study is divided into two sections. The two cases include the well-being issues observed among them. The study point to the issues that they are currently facing in society as well as within their own family circle.

1. THE CASE OF SIAMMAWII RALTE

Siammawii Ralte is a 31 year old woman who resides in Bazar Veng, Lunglei, Mizoram, which is located at the hub of the town. It is an area which is fairly crowded as compared to the rest of Lunglei town. It is also the commercial hub centre of Lunglei. Their house is an Assam-type house which is small yet, has two floors. It is situated beside the main road.

Although Siammawii Ralte is a 31 years old woman, she behaves and looks like a teenage girl. They have a small plot of land and are not a well to do family. She is not taken care of by her parents due to undisclosed problem which led her aunt to take care of her. It can be known from her

aunty that the separation of her parents is more stressful than her conditions. She was born with the intellectual disability and also develop spastic at a later stage of her life. She was diagnosed with mental illness at a later stage in her life. She did not receive any formal type of job oriented training and also did not receive any professional help, though registered under Unique Disabilities Identity (UDID) Card. She did not receive any professional help except having a certificate on being registered under UDID.

She regularly attends Onix Special School which is located in Chanmari, Lunglei. Her education as of now is very limited indeed. She can write the names of the months and days and several types of vegetables and animals. At school, she is one of the most reliable students and often acts as a leader and guides the other special students in their tasks, as revealed by her mentor. She obeys her teachers and is all willing to co-operate accordingly. She is often the spokesperson of their school and is loved and adored by her teachers and her friends. 'Although she is a bit stubborn at times, she is one of the most reliable students that we have', said her teacher mentor. She also swept the floors of her classroom and feed the other children as and when necessary.

She relies heavily on her aunt and her grandmother for almost all the tasks in their house and simply sits and watches the television or watch the smartphones. She is healthy and often do not have problems in terms of health. 'We are blessed by the Almighty God as Lalliani is amazingly healthy since her birth and do not require medical attention as much,'said her aunt.

In terms of women specific problems, her aunt said that they faced quite a lot of problem when she had her menstrual cycle. Before the advent of her monthly period, she would face certain problems which are difficult to describe. Sometimes she would shout as loud as possible and disrupt the whole neighbourhood. Her aunt said, '...at one point, she even took a cab to Zobawk village and went there before her monthly period starts.' The only problem that they have faced is during her menstrual cycle which disrupts not only the family but the whole neighbourhood as well. The patience and support of the neighbours have left them feeling grateful and ease their burden.

Her aunt went on to describe the absence of proper guidance and training centres to be the main problem that they face. The schools are still not inclusive and the inclusive development is still not up to expectation in

Mizoram. There are still some people who would mock them and laugh behind their backs which hurt their feelings. There is also one incident which hurt their feelings even up to this day.

The family of Siammawii Ralte cope with her disability by accepting her as she is and also accepting her disability. Since there is nothing much they can do to improve her conditions, they just simply accept her as she is and love her endlessly even when she is disobedient and rebel against her families. Her aunt would often tell her to do household chores and would even show her how to do it properly but would not engage in any chores. This would often lead her aunt to scold her.

2. THE CASE OF THANGLURA

Thanglura and his family lives in Zemabawk, which is located in the northern part of Aizawl, Mizoram. His family lives in a small house and their denomination is Salvation Army. Although all the members of his family are hard-working, Thanglurais not in a condition to work any type of job and would just wander around the city. He has a mental illness and did not receive any professional help and also did not receive any type of vocational training and education.

In terms of land possession, they have a 0.21 to 0.41 hectare of land and come from a middle class family. Thanglura did not receive any type of vocational training or professional help. He also did not receive any type of education as he is not capable of learning anything. His disability started right from his birth but is fortunate enough as he never have any type of major illness. Although he is confident to move freely on his own, he used to wander very far from his house and family which would often prove to be problematic for his family. There are days when they had to search for him but fortunately, he would eventually find his way home without much problem.

His disability has affected his entire family as the family members would often argue with one another in terms of treatment given to him. Financially, it also affects his families as well. However, his families never leave his side when he needs them. The major problem that they faced is in terms of financial support.

‘It would really be great if the Government could regularly give old age pension to old disabled people as finances spent for them is very extensive and problematic.’ – Thanglura’s caregiver.

His caretaker had said that orientation and training centres are very limited for the disabled which hinders their growth.

‘It would be best if there are a sizeable amount of training centres and vocational schools for the disabled as that would help them to be financially independent and would also boost their confidence...’said his caretaker.

The discrimination directed towards the disabled people is still visible in society and are still excluded from various social programmes. Their exclusion hurt the feelings of their families and in turn blocked their chances to be integrated with the mainstream society.

The societal prejudice towards disabled people, especially those who are mentally ill have a great toll on the family as it often leads to exclusion and isolation. Even though the neighbours and society in general may not necessarily mock and make fun of them, the prejudices that they are not worthy to do anything led them to be excluded from various functions around the localities.

His caretaker went on to say that, ‘..mental illness is a huge issue which disrupts the normal functioning of normal people but the seriousness of the issue doubled when it happens to people with disabilities and their caregivers.’

DISCUSSION

These case studies point to the fact that all the respondents did not have any access to professional help to cope with their problems instead relying solely on the limited help and support of their own family members. The unfortunate part of the two case studies is that mental illness patients are deeply affected by the illness and the problem even extend to their family members who also share a fair amount of hardships and problems while raising them. The two case studies also reveal that all the two patients are not economically well off to run the family and all had financial problem while coping with the mental health issue. Even though their caregivers love and support them, there are a many times when they feel depressed while looking after them. They each had to endure some family conflict while looking after their mentally ill family member as well. Thetwoparticipants did not receive any type of job-oriented training due to the unavailability of such in the state and are also not in a condition to do so as well. They more or less depend entirely on their families. Since looking after persons with mental illness require extra hours as compared

to normal children, the caregivers and family members of the two patients often have to deal with long lasting effect on their mental health. The discrimination faced in terms of teasing or exclusion or denial of certain necessities in society hurt them deeply and makes them want to isolate themselves more from the rest of society. Their parents are also stigmatised at times which makes them feel insecure at some point. The participants also faced stigmatisation and prejudices around neighborhood relations and day to day interactions which deeply affected them. It is still believed by some handful of people that disability stems from the sins committed by the parents and is punished by God by giving them a disabled child. Besides, while choosing for a partner, many families carefully judge whether disability runs in the family and will deny the marriage proposal if there are any such cases within the other family. These kinds of stigmatisation are still faced by the families of people with disabilities which also hurt their self-esteem and have a toll on the mental health of the families and caregivers. Another common practice among the caregivers is that none of them have never discussed the family problems with their friends and neighbours. The main reason is that they felt like their situations are difficult to understand by the general public and then there are also some activists which use their misfortune for their own benefits.

These narratives put religious and social model of disability to context. The difference among the two patients is that even though they both had mental illness, their conditions are different. While Thanglura had no problem roaming around the streets, Siammawii Ralte had to be escorted all the time. Thanglura, on the other hand, finds comfort by roaming around the streets and is not comfortable staying at one particular place. His caretaker had even said, ‘..it is very difficult to take care of Thanglura as he had his own opinion and since no one in the family is trained to look after persons with mental illness, it often proved to be problematic for the family.’

This section looks back to the issues raised in the beginning and presents an overview of the text and context. As mentioned in the moral and religious model of disability given by Henderson and Bryan (2011), the sins committed by the parents in their past life did not go unpunished which led to the birth of a disabled child in their. Similarly, this belief is still not erased among the general public in Mizoram. A clear example is seen in the case of Siammawii Ralte in which people blamed her disability due

to the past sins of her ancestors, a stigma which clearly had a tremendous effect especially on her caregiver. Brennan et.al (2018) has stated that parents and caregivers of disabled child are burdened with work life challenges as is observed in the all the caregivers of the two case studies mentioned. They are constantly under stress as they are looking after their mentally ill family member in which they did not have much time to look after even themselves. Besides, as compared to parents who raise normal children, they faced double, even triple the amount of stress and challenges which also have a toll on their mental and physical health as well. Brennan et.al (2018) have also stated that parents of special children spent at least 11 hours looking after their children which is far more as compared to parents who are raising normal children. These instances have also been observed among the two case studies where the caregivers have to spent a considerable amount of time to care for and look after their mentally ill family member.

The case studies show that even though certain measures are taken towards the rehabilitation and inclusive development of the persons with disabilities, it is still not enough as even the current resources for disabilities did not extend to all the persons with disabilities in the state. Hence, the non-availability of resources and improper implementation of schemes for the persons with disabilities further add to their discrimination and this led to the further decline of the mental health conditions of both the participants and their family members. It is also clear that Mizoram still has a long way to go in terms of providing assistance to the persons with disabilities. The absence of proper guidance and counselling centres for mentally ill and other persons with disabilities have a tremendous effect on the lives of both the participants and their family members as well.

SCOPE AND LIMITATIONS

This study has some practical implications as it views well-being issues of people with mental illness from a sociological point of view and also presents an in-depth analysis of the issues faced by them in their family as well as in society. The qualitative study of the well-being issues of the participants also shows that clinicians and other researchers should also focus on the stigmatisation and discrimination associated with mental illness in their study.

The first limitation with regard to the study is that participants are very few and may not properly represents all people with mental illness in

Mizoram. Secondly, the participants themselves informed about their diagnosis of mental illness and it was difficult to know about the exact level of their mental illness and diagnosis was difficult since the researcher is not trained in that field. Thirdly, the participants and their caregivers did not know the exact reason for the onset of mental illness in their family members.

CONCLUSION

It would be in proper perspective if the government could monitor and take utmost care of at least all the Unique Disabilities Identity (UDID) card holders. It would also be helpful to ease the burden of the family of persons with disabilities if strict and proper implementation of laws for persons with disabilities are maintained and also if UDID certificates are properly utilized which would benefit the UDID holders. Proper awareness with regards to the importance of care and inclusion of persons with disabilities within society is also much needed which can elevate their confidence and self-confidence. Besides, easy access to public buildings, inclusivity in education and workplace and the provision of vocational and job oriented training is highly necessary in Mizoram which could make them independent in some aspects of their life which would definitely assist their mental health conditions to a considerable extent.

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