

Lived Experience of Mothers with Duchenne Muscular Dystrophy Children, Kathmandu

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Abstract:

Introduction: Duchenne Muscular Dystrophy (DMD) is a genetic neuromuscular disorder with functional disability. In Nepal, eight hundred cases have been registered in Muscular Dystrophy Foundation (MDF). The Survival age of child with Duchene Muscular Dystrophy (DMD) is not more than twenty four years of life. (MDF-Nepal). The purpose of this study was to explore the lived experiences of mothers who are taking care of children with muscular dystrophy.

Methods: Using a phenomenological design, nine mothers having DMD children were selected. Data was gathered using In-depth interview method. Respondent's verbal as well as nonverbal clues were recorded during observation. Two to three in-depth interviews were carried out with each respondent along with audio tape recording and field notes.

Results: Almost all of the respondents perceived DMD as a progressive fatal form of neuromuscular disease making the child unable to walk by 7-8 years of age. Majority of the respondents had suffered from psychosocial problems as well. The initial reaction of mothers regarding children's diagnosis was a feeling of mixed emotion. Majority of the mothers relieved their anxiety to some extent by sharing their feelings with others, assuring themselves and accepting their reality of their child's illness. Clusters of themes were identified: perception regarding disease, treatment modality, physical mobility of child, and coping mechanisms.

Conclusion: Mothers of DMD children are facing a huge array of problems which has decreases the quality of life of mothers. It is recommended to provide, social security, free supply of medicine, health facility and Palliative care for DMD child so that parents may face fewer problems.

Key Words: Duchenne Muscular Dystrophy, child, Physical disability

Introduction

Duchenne Muscular dystrophy (DMD), a genetic killer is defined as a group of human genetic disorder characterized by progressive muscle wasting and microscopic changes in the muscle. There are many types of Muscular Dystrophy(MD). Among them, Duchene Muscular dystrophy (DMD) is the commonest X-Linked form¹. DMD is the disabling genetic condition that can happen to any family at any time. Both sexes are affected, though female are rarely affected and they are the carriers. DMD is the most common form of MD affecting 1 out of 3,500 boys². In Nepal, Eight hundred cases been registered in Muscular Dystrophy Foundation (MDF).

It can be detected with about 95% accuracy by genetic studies performed during pregnancy.² Children are often diagnosed between the ages of 3 and 6 years old; they usually show signs of muscle weakness when walking and fall frequently and usually lose the ability to walk by age 12. Children usually do not begin to walk until about age 18 months or later⁶⁻¹⁰. The progression of the disease occurs in four stages, which include the early stage (diagnosis to 7 years of age), the transitional stage (6 to 12 years of age), the loss-of-ambulation stage (8 to 14 years of age), and the adult stage (15 years of age)¹¹. The average life expectancy for patients afflicted with DMD varies from late teens to early to mid 20s⁷.

Researchers have concluded that families with children with DMD need additional services and support to help them better cope and care for their children. Parents of children with neuromuscular disorders are more likely than parents of healthy children to report poor health, financial burden, and pessimism.¹³ Disruptions in family lives begin as soon as muscle weakness interferes with activities of daily living⁸.

In developing countries like Nepal, prevalence of diseases and major causes of deaths could more likely be communicable/infectious disease but the burden of Non -Communicable Disease (NCD) cannot be underestimated. According to WHO, (2002) NCD is estimated to be responsible for 6.7 of all deaths in Nepal. DMD falls under NCD and prevalence of DMD child is more than 25,000 even though it is back of light. Though the budget forecast by the government is Rs.1000/month to severely disabled persons as a social security, the decision regarding the categorization of severity of the disabilities is not yet clear.

There is not a single qualitative research done on MD in Nepal. Official data, specific health policy, and legal framework in support of diagnosis and rehabilitation of MD in Nepal are not sufficient. There is scarcity of qualitative information regarding the feelings of parents, difficulties they are experiencing, feelings of hope for cure and lastly anticipation of the parents that the end is near for the child is so painful and devastating that needs to be explored.

Methods

Qualitative research approach with phenomenological design was adopted. The populations of the study were mothers only who were taking care of their DMD children who were in transitional phase at Muscular Dystrophy Foundation's office (MDF) and also at respondent's home too. Non-probability purposive sampling was used for the selection of mothers. Altogether 9 cases were included in the study. Data were collected after obtaining permission from the research committee of Nursing Campus Maharajgunj and concerned authorities by submitting official request letter. Formal permission was taken from the president of MDF -Nepal for data collection. Throughout the study precautions were taken to safeguard the rights of the respondents. Informed verbal consent was obtained from all the respondents. Permission was taken for audio taping of the interview. Privacy was maintained by assuring them that the information given by them will be kept confidential and used only for the purpose of this study. Liberty was given to them to discontinue the study at any time if they wished.

Researcher herself conducted the in-depth interview for the clarity of the data by using open-ended interview guidelines. Interview was started with grand- tour questions then probing (specific) questions. In average 3-4 visits were made for each respondent for the purpose of interviewing. For credibility of data, researcher gave prolonged time period in the field and revisits were made. The audio taped interview was checked after the completion in order to confirm that it was well recorded or not, and then it was labeled by giving code number. Each interview lasted for about 45-60 minutes.

The Process of data analysis was started along with the data collection. The audio tape was listened repeatedly again and again unless and until the researcher was well familiar with actual information and could get a feeling of the experiences of the participants and then write in detail about their experiences in paper as shown in conceptual framework in figure.

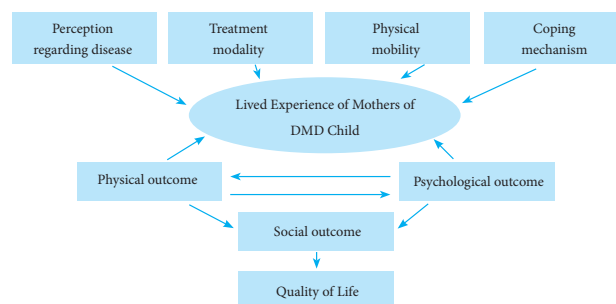


Figure 1 Conceptual Framework developed based on the findings of the study of lived experience of mothers of DMD children

Expansion of information was done and reduced to a single statement that was meaningful or significant for the purpose of the study. Extracted special meaning was coded and certain responses that occurred were noted. The researcher again reconfirmed the experiences transcribed with the respective respondents by making revisits. Thematic content analysis as developed by Gibson (2006) was used to interpret the qualitative findings: all together 171 items were identified at the first level of analysis.

Results

Socio-demographic respondents are presented in terms of age, ethnicity, religion, education level, and marital status of the respondents. The respondents' age ranged from 27yrs to 50yrs. In terms of religion, two -thirds of the respondents followed Hinduism religion followed by Buddhism and Christianity respectively. Regarding educational status, all were literate. In regards to the occupation, half of the respondents were homemakers.

Almost all of the respondents (7/9) belonged to nuclear family.

Majority of the respondents (7/9) responded that Duchenne Muscular Dystrophy is a fatal form of neuromuscular disease which is progressive in nature and affects the muscle making child unable to walk by 7-8 years. In response to the reaction after diagnosis, seven participants felt shocked and numb whereas other two felt helpless. Two respondents said *"they felt like falling from high cliff"*, whereas others remained socially isolate as, they didn't talk with anyone for a several weeks.

Experiences regarding treatment modality, all of the respondents had sought modern treatment. They had visited hospitals, special clinics, and Muscular Dystrophy Foundation for the treatment followed by alternative therapy respectively. Some participants did religious practices, some went to the traditional healers and very few did oil massage in home.

Experiences regarding coping mechanisms, many mothers (7/9) said that they relieved their anxiety to some extent by means of religious practices. They continued to pray, worshipped God, keep fasting (*bratae*) for the welfare of their children, visited temples and Devmatas, followed by sharing the problem with others, assuring themselves, accepting the problems and using the recreational practices.

Although they have been helped, they need greater assistance or a supporting staff to take care of their child and help them in their household works too. They felt helpless and faced emotional torture. Regarding financial burden, although they were residing in Kathmandu, most of the respondent's origins were from outside the valley. Majority of the respondents (7/9) belonged to middle class family and the income was fine. Whereas two mothers (2/9) belonged to low class family and the cost of rent, school's fee, and cost of therapy created financial burden for them. One mother said, *"I am not able to generate extra income because of time needed in caring for my child and doing household chores, life is too difficult"*.

Regarding governmental support, majority of the respondents (6/9) didn't get any support from the government or any other concerned institutions. They expressed their wish to get some support and even had gone to demand support, but in vain whereas, one mother got support from government. Others mothers got support from MDF Nepal that gave them wheelchairs along with medicines, physiotherapy, frequent health checkups and monitoring the children's muscular strength.

More than half of the respondents (6/9) had sound marital relationship followed by (3/9) marital disharmony. Regarding social obligations seven respondents (7/9) remained detached from it because of no extra leisure time whereas four (4/7) respondents were rejected by their in-laws who did not behave well.

Experiences regarding schooling, more than half of the mothers (5/9) reported experiences of being supported from school. Their children were keenly observed and the teachers behaved well. One of the mothers said, *"The teachers as well as his friends adore him and care for him. We pay only half the tuition fees. His friends show special care, sometimes by carrying his bags and helping him."*

Regarding burden and satisfaction, seven out of respondents (7/9) felt burdened because of their child's condition. Most of the mothers felt aggrieved and troubled to see their child suffer day by day. Watching their sons' condition degrading slowly, from walking condition to immobility has made their lives a whirlpool of tumbling emotions and difficulties. Six mothers (6/9) expressed that they received satisfaction when they took proper care of their child. They felt happy when they saw their child being happy and smiling. Providing and fulfilling their child's wishes, giving them time and attention made the mothers happy and satisfied. Irrespective of the poor financial status of the family, love and care that the child received from their mothers was the source of contentment and joy. Two of the respondents articulated sadly, *"I hope he passes away before I do."* These two mothers cannot bear to see their child suffer with the disability, so they are willing to sacrifice their happiness and endure sadness for the rest of their lives instead of their child.

Table 1 Disease Profile of DMD children

Cases	Age	No. of sibling	Similar kind of disease in family	Developmental disorders in child		
				Delayed walking	Frequent fall	Learning difficulty
Code A	9 yrs	B-1(19mths)	No	Yes-18mths	Yes (5yrs)	No -Grade2
Code B	18 yrs	S-1(23yrs)	Yes-Maternal uncle (died)	Yes -18mths	Yes (5-6yrs)	Yes-U.K.G.*
Code C	14 yrs	S-1(18yrs)	No	Yes -16mths	Yes (5yrs)	No-Grade6*
Code D	7 yrs	B-1(12yrs)	No	No	Yes (2yrs)	No -Grade4*
Code E	9 yrs	S-1(15mths)	No	Yes -3yrs	Yes (3yrs)	No- U.K.G.
Code F	10 yrs	None	No	Yes-2yrs	Yes (2yrs)	NO -Grade2
Code G	5 yrs	None	No	Yes -2yrs	Yes(2.5yrs)	No -L.K.G.
Code H	9 yrs	None	Yes-maternal uncle (18yrs)	Yes -15mths	Yes (3-4yrs)	Yes-U.K.G.*
Code I	12 yrs	S-1(8yrs)	No	Yes -2yrs	Yes (3yrs)	Yes -Grade4*

Keys: *- left school, B-Brother, S-Sister

Table 2 Condition of DMD children

Cases	Age of the child	Perform Activities of daily living		Functional Mobility		Bed side mobility		Gower's sign
		Self	Need assistance	Can walk	Wheel chair bound	Self	Need Assistance	
Code A	9yrs	-	Yes	Yes	-	Yes	-	Yes
Code B	18yrs	-	Yes	-	Yes	-	Yes	-
Code C	14yrs	-	Yes	-	Yes	-	Yes	-
Code D	7yrs	Yes	-	Yes	-	Yes	-	Yes
Code E	9yrs	Yes	-	Yes	-	Yes	-	Yes
Code F	10yrs	Yes	-	Yes	-	Yes	-	Yes
Code G	5yrs	-	Yes	Yes	-	-	Yes	Yes
Code H	9yrs	-	Yes	-	Yes	-	Yes	-
Code I	12yrs	-	Yes	-	Yes	-	Yes	-

Discussion

Most of the respondents reported that the muscular dystrophy was a fatal form of neuromuscular disease which is progressive in nature and affects the muscle rendering child unable to walk by 7-8 years. The findings are consistent with the report of Bothwell². In this study, respondents answered that their initial reaction to the children diagnosis were a feeling of mixed emotions which included being shocked, numb and helpless which was painful and devastating. Similar findings were reported by Samson A¹⁴.

Respondents reported that they had faced enormous psychosomatic problems such as decreased appetite, tiredness, insomnia, headache, pain, heaviness in the chest. Similar findings were reported by Nereo N.E.¹³. In this study, all the mothers had experiences of mobility problem in their child and some mothers reported that children's chest heaves forward while walking.

Most of the respondents have great belief in modern treatment as they sought for it followed by alternative therapy. They tried the treatment process doing every effective possible ways. Similar findings were revealed by Samson et al¹⁴. They did not get much support from relatives. Most of them are in stress and remain aloof. They experienced marital disharmony too. Majority of the mothers attend to fewer parties and do not often visit relatives as they spend more time looking after their child. Similar findings were reported by Nereo N.E.¹⁵

Regarding coping mechanisms in this study, majority of the respondents said they relieved their anxiety to some extent by sharing their feelings with others, accepting the problems and doing recreational activities.

Conclusion

All the mothers perceived DMD as a fatal neuromuscular disease. They experienced obstacles in different aspects of their life because of their limitation of child mobility and reflected much psychosomatic problems. Their immediate reaction after hearing the children's diagnosis was found to be mixed emotions due to progressive nature of the disease and they have difficulties in continuing their work in social activities. Another problem is related to finance because they have to spend more time with their child. They relieve their anxiety to some extent by sharing their feelings with others, assuring themselves, accepting the reality of their child's illness, and engaging in recreational activities. Hence, it can be concluded that this study shows that the mothers of DMD children face a huge array of problems which decreased the quality of life of mothers.

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