ORIGINAL ARTICLE

Quality Of Life And Coping In Parents Raising Children With Duchenne Muscular Dystrophy (DMD) In Nepal

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Abstract

Introduction: *Quality of Life (QoL) and Coping are important components of mental health, especially important to parents raising children with Duchenne Muscular Dystrophy (DMD). Children with DMD face difficulties due to their disability and create special challenges for parents.*

Material And Method: *The study aimed to assess QoL, demographic variables and coping strategies of parents raising children with DMD in Nepal. A descriptive cross-sectional design was adopted to collect data from 32 parents (mothers = 15, 47%; fathers =17, 53%) through purposive sampling. Socio-demographic pro-forma, World Health Organization's Quality of Life Questionnaire-BREF (WHOQOL-BREF) and Brief COPE Inventory were assessed.*

Results: *The results revealed parents scores were below cutoff <60, indicating probable poor quality of life. QOL was moderately positively correlated with coping strategies and highly positively correlated with emotion-focused coping. There were significant differences in psychological health of parents in reference to their occupation, and in reference to their hospital born children. Parents in government job had better psychological health and parents into private business significantly used emotion-focused coping. Mutual caregivers had significantly better psychological health. Parents without health related problems significantly adopted problem focused coping and emotion focused coping.*

Conclusion*: These findings will help stakeholders to understand DMD children and their impact on QOL and coping of parents and will facilitate to develop appropriate psychosocial intervention programs for the parents for the effective management of their children and their psycho-social wellbeing.*

Keywords: Coping Strategies, Duchenne Muscular Dystrophy, Quality of Life.

INTRODUCTION

Duchenne Muscular Dystrophy (DMD) is an inherited X-linked recessive neuromuscular disorder found to be the second most common genetic disorder which has an estimated incidence of 1 in 3500 live births in male infants and in about 1 in 50 000 000 female births.[1-3] It is caused by the lack of the protein dystrophin which affects the skeletal muscles, leading to damage and eventual death of muscle cells. This leads to progressive muscle wasting, which eventually results in severe debilitation [2]. DMD patients usually lose movement between age 8 and 12 years and succumb to death by the third decade due to cardiac or respiratory complication.[4]. However, life expectancy is increasing because of proactive care and more aggressive treatments.

Six hundred eighty nine cases have been registered in Muscular Dystrophy Foundation Nepal (MDF-Nepal).[5] DMD presents parents with many challenges and mothers, in particular, have added burden knowing that they are the unwitting carriers of the mutation responsible for the disorder. Thus, they may develop an attitude of self-blame.[6] Parents usually react with disbelief, anger, guilt, fear, confusion, powerlessness, rejection and parent/child-related stress.[6-8] In a similar study in regard to parental stress, about 46.67% parents reported to have high level of stress. Parents experienced greater level of stress with children having low intelligence.[9] A child's disabilities and distresses burdens the family members, especially the parents, who are their long-term caregivers.[10] Parents of children with neuromuscular disease are pessimistic about outcomes relating to the disease and may have negative feelings toward the children. Children with disabilities affect their parents' quality of life (QoL) as they need to spend most of their time taking care of their disabled child and the parents are then unable to engage in other activities, curtailing their social life and negatively affecting their QOL.[11] This is evident with parents of DMD children.

QOL is a multidimensional phenomenon encompassing physical, mental, and social functioning and well -being.[12] World Health Organization defines QOL as "an individual's perception of his/her position in life, in the context of the culture and value systems in which s/he lives, and in relation to goals, expectations, standards and concerns." [13] Within the framework of this study, QoL is the degree of satisfaction felt by parents of children with DMD towards the various dimensions of life, as the level of satisfaction with life; physical, psychological, social and environmental covering a satisfaction with material and moral sides, interaction with the family and social relations, getting social support, practice of daily activities, the ability to pursue happiness and optimism resulted from the psychological readiness of the individual, and the role of others and their ability to provide support to interact with the surrounding environment.

Coping is a cognitive or behavioral response to a situation appraised as stressful. Coping processes used by caregivers can be grouped into two types: problem-focused strategies (i.e. to alter or manage the situation in an active and constructive way) and emotion-focused strategies (i.e. to relieve the emotional impact of the stressful situation by using thoughts and indirect actions).[14] Individuals use a range of specific responses of both types, sometimes at the same time and to varying degrees. There is no clear consensus regarding which type of coping strategy is most effective for maintaining positive mental health because coping strategies may have different types of stressor. Further distinction between approach coping (i.e., strategies aimed at dealing actively with the stressor or related emotions) and avoidance coping (i.e., strategies aimed at avoiding stressful situations) were established.[15*] Studies based on coping skills of parents whose children have disabilities, although scant, add valuable information to the research literature. A study suggests that coping skills studies have greater implications for understanding and improving ways to help. It concluded that a consistent finding in both qualitative and quantitative studies is the usefulness of active coping strategies.[9]

MATERIAL AND METHOD

The study objectives were to identify QOL and coping strategies of parents raising children with DMD. Cross sectional research design was used with quantitative methods to collect and analyze data. Information was collected at the MDF- Nepal annual health camp-2018. After informed consent, purposive sample of parents (n= 32) of DMD children and children (age up to 19 years) diagnosed with DMD (n=32) were included. The socio demographic pro-forma, the WHOQOL-BREF and the Brief COPE were utilized. The WHOQOL-BREF developed in 1998, is a short version of the WHOQOL-100, a self-administered questionnaire. It is a multidimensional, conceptualized, generic, 26-item self-administered independent questionnaire.[16] It comprises of 26 items categorized into four broad domains: physical health, psychological health, social relationships and environment health. It is an easily administrable and a valid and reliable instrument. Scores below cutoff <60, indicated probable poor quality of life. QOL Cronbach's alpha for the total QoL score was .91 in Arabic version and is sensitive to the Health Related QOL.[17-18] Numerous studies in Nepal have used WHOQOL BREF and it has been translated in Nepali version. The Brief COPE Inventory developed by Carver (1997), consists of 28 items divided into 14 subscales, administered in 10 minutes, theoretically identifies coping responses: Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, and Self-blame.[19] Higher the scores indicate the greater use of each coping strategies. Three composite subscales measuring emotion-focused, problem focused and dysfunctional coping have proved useful in clinical research and have content validity.

Ethical approval was obtained from the Institutional Review Board (IRB), Institution of Medicine (IOM), Tribhuvan University. The parents were explained about the benefits of the study; to improve their QOL and adaptive coping. There was no harm or any kind of financial burden to the children or their families from the study. The collected data were analyzed using Statistical Package for the Social Sciences (SPSS) version 20 and results expressed using the descriptive statistics; frequency, percentages, means and standard deviation; and the inferential statistics for instance t-test, chi square and correlation were used as appropriate.

RESULT

Reliability Analysis of test instruments

Test instruments	**Cronbach's alpha (α)**
WHO Quality of Life BREF	0.77
Brief COPE Inventory	0.74

In this study, the internal consistency of WHO QOL BREF's Cronbach's alpha (α) score was 0.77 and Brief COPE Inventory's Cronbach's alpha (α) score was .74, which indicates good internal consistency and reliability of both the scales.

Table 1 illustrates the socio-demographic characteristics of the parents of DMD children.

Table 2 demonstrates there were no significant differences on the socio-demographic conditions among the children with DMD.

Though there was no significant findings in the QoL of parents, however, the results indicate the QoL mean scores were lower than cut-off score of 60 which indicates lower than average QoL. (Table 3) Psychological health (F = 3.012, $p<0.05$) and environmental health (F = 2.511, $p<0.05$) of parents were found to be significantly better with hospital born children. Mutual caregivers had significantly better psychological health (F=3.319, p<. 010). (Table 4)

There were significant differences on psychological health of parents according to the occupation of parents (F = 2.479, $p<0.05$). (Table 5) Parents significantly used problem focused coping (F = 3.132, $p<0.05$) and emotion focused coping (F = 3.117, $p<0.05$) when they did not have any health related problems. Similarly, parents into private business significantly used emotion-focused coping (F = 2.574, $p<0.05$) and parents of Hindu religion (F =3.855, $p<0.05$) also significantly used emotion focused coping. (Table 6)

Emotion focused coping was significantly used (F = 2.338, $p<0.05$) by parents while taking care of a female child. Avoidant coping (F = 2.823, $p<0.05$) was significantly adopted by parents when children were diagnosed at 8-12years. Social supported coping (F = 2.628, $p<0.05$) was significant when child was diagnosed with DMD during 4 -7 years. Problem-focused coping was significantly adopted by parents with toilet trained children (F = 3.576, $p<0.05$). (Table 7)

QOL had moderate level of positive correlation with the coping strategies (r =+. 389, $p<0.05$) and high level of positive correlations with emotion-focused coping (r =+. 475, $p<0.01$). Psychological health had moderate level of positive correlation with problem focused coping (r = +. 355, $p<0.05$) and avoidant coping (r =+. 443, $p<0.05$) and high level of positive correlation with environmental health (r =+. 492, $p<0.01$), whereas physical health had moderate level of positive correlation with psychological health(r = +. 444, $p<0.05$) and emotion focused coping (r = +. 386, $p<0.05$). Social relationship was highly positively correlated with environmental health (r =+. 481, $p<0.01$) and moderately positively correlated with emotion focused coping (r = +. 372, $p<0.05$). Problem focused coping was highly positively correlated with emotion focused coping (r =+. 505, $p<0.01$) and social support coping (r =+. 638, $p<0.01$) and emotion focused coping was also highly positively correlated with social support coping (r =+. 514, $p<0.01$). (Table 8)

Table 1: Socio-Demographic Profile Of Patients

Socio-demographic Variables		Fathers (n=17, 53%)	Mothers (n=15; 47%)	Total (n)	Chi-square
Age	20-29	1 (3%)	3 (9%)	4 (13%)	χ2 = .577 df = 4 p= 2.886 (NS)
	30-39	6 (19%)	6 (19%)	12 (38%)	
	40-49	6 (19%)	3(9%)	9 (28%)	
	50-59	3 (9%)	3 (3%)	6 (19%)	
	60-69	1 (3%)	0 (0%)	1 (3%)	
Education	Illiterate	1 (3%)	3 (9%)	4 (13%)	χ2 =.893 df = 5 p= .1667 (NS)
	Primary Level	4 (13%)	3 (9%)	7 (22%)	
	Secondary Level	4 (13%)	3 (9%)	7 (22%)	
	Higher Secondary	5 (16%)	3 (9%)	8 (25%)	
	Bachelor's Degree	1 (3%)	1(3%)	2 (6%)	
	Master's Degree	2 (6%)	2 (6%)	4 (13%)	
Occupation	Government Job	5 (16%)	1 (3%)	6 (19%)	χ2 = .156 df = 5 p= 8.006 (NS)
	Private Business	5 (16%)	3(9%)	8 (25%)	
	Freelance	2 (6%)	1 (3%)	3 (9%)	
	Wage Worker	2 (6%)	2 (6%)	4 (13%)	
	Homemaker	3 (9%)	8 (25%)	11 (34%)	
Religion	Hindu	15 (47%)	11 (34%)	26 (81%)	χ2 = .320 df = 3 p = 3.504 (NS)
	Buddhist	1 (3%)	3 (9%)	4 (13%)	
	Christian	0 (0%)	1 (3%)	1 (3%)	
	Others	1(3%)	0 (0%)	1 (3%)	
Caste/ Ethnicity	Brahmin	5 (16%)	7 (22%)	12 (38%)	χ2 = .222 df = 7 p = 9.445 (NS)
	Chhetri	6 (19%)	2 (6%)	8 (25%)	
	Tamang	2 (6%)	0 (0%)	2 (6%)	
	Newar	2 (6%)	3 (9%)	5 (16%)	
	Magar	0 (0%)	1 (3%)	1 (3%)	
	Gurung	1 (3%)	0 (0%)	1 (3%)	
	Kirat	1 (3%)	0 (0%)	1 (3%)	
	Others	0 (0%)	2 (6%)	2 (6%)	
SES	High Middle	0 (0%)	1 (3%)	2 (6%)	χ2 = .109 df = 3 p = 6.052 (NS)
	Middle	14 (44%)	12 (38%)	26 (81%)	
	Low Middle	0 (0%)	2 (6%)	2 (6%)	
	Low	3 (9%)	0 (0%)	3 (9%)	
Residence	Kathmandu Valley	6 (19%)	10 (31%)	16 (50%)	χ2= .076 df = 2 p = 5 .162 (NS)
	Out of Valley	11 (34%)	5 (16%)	16 (50%)	
Family Type	Nuclear	12 (38%)	8 (25%)	20(63%)	χ2 = .412 df = 2 p = 1.773 (NS)
	Joint	7 (22%)	7 (22%)	12 (38%)	
Training on MD	Trained	4 (13%)	4 (13%)	8 (25%)	χ2 = .838 df = 1 p = 0.42 (NS)
	Untrained	13 (41%)	11 (34%)	24 (75%)	
Health related Problems	Illness	3 (9%)	2 (6%)	5 (16%)	χ2 = .737 df = 1 p = .112 (NS)
	No Illness	14 (44%)	13 (41%)	27 (84%)	
Support for primary Caregiver	No support	1 (3%)	1 (3%)	2 (6%)	χ2 = .669 df = 3 p = 1.428 (NS)
	Spouse	11 (34%)	10 (31%)	21 (66%)	
	Grandparents	5 (16%)	3 (9%)	8 (25%)	
	Friends/Relatives	0 (0%)	1 (3%)	1 (3%)	

NS = Not Significant

Table 2: Socio-Demographic profile of Children

Socio-demographic		Male Child (n = 26)	Female Child (n = 6)	Total (n= 32)	Chi-square
Age	0-3	0 (0%)	0 (0%)	0 (0%)	χ2 = .277 df = 2 p = 2.565 (NS)
	4-7	4 (13%)	1 (3%)	5 (16%)	
	8 -11	8 (25%)	0 (0%)	8 (25%)	
	12-19	14 (44%)	5 (16%)	19 (59%)	
Birth Place	Home delivery	9 (28%)	0 (0%)	9 (28%)	χ2 = .089 df = 1 p = 2.890 (NS)
	Hospital	17 (53%)	6 (19%)	23 (72%)	
Age of Diagnosis	0-3	6 (19%)	2 (6%)	8 (25%)	χ2 = .909 df = 3 p = .543 (NS)
	4-7	11 (34%)	2 (6%)	13 (41%)	
	8 -11	8 (25%)	2 (6%)	10 (31%)	
	12 and above	1 (3%)	0 (0%)	1 (3%)	
Birth Order	1st	11 (34%)	4 (13%)	15 (47%)	χ2 = .684 df = 3 p = 1.493
	2nd	12 (38%)	2(6%)	14 (44%)	
	3rd	2 (6%)	0 (0%)	2 (6%)	
	4th	1 (3%)	0 (0%)	1 (3%)	
Siblings	No Siblings	2 (6%)	0 (0%)	2 (6%)	χ2 = .472 df = 3 p = 2.519 (NS)
	One Sibling	15 (47%)	4 (13%)	19 (59%)	
	Two Siblings	4 (13%)	2 (6%)	6 (19%)	
	More than two	5 (16%)	0 (0%)	5 (16%)	
Speech	Verbal	24 (75%)	4 (13%)	28 (88%)	χ2 = .087 df = 1 p = 2.930 (NS)
	Non-Verbal	2(6%)	2 (6%)	4 (13%)	
Toilet Training	Trained	16 (50%)	2 (6%)	18 (56%)	χ2 = .442 df = 2 p =1.633 (NS)
	Untrained	10 (31%)	4 (13%)	14 (44%)	
Behavioral Issues	Calm	13 (41%)	4 (13%)	17 (53%)	χ2 = .426 df = 5 p = 4.914 (NS)
	Hyperactive	5 (16%)	0 (0%)	5 (16%)	
	Aggressive	6 (19%)	1 (3%)	7 (22%)	
	Offensive	1 (3%)	0 (0%)	1 (3%)	
	Multiple issues	1 (3%)	1 (3%)	2 (6%)	
Social Problems	No Problem	11 (34%)	2 (6%)	13 (41%)	χ2 = .829 df = 6 p = 2.840 (NS)
	Market place	2 (6%)	0 (0%)	2 (6%)	
	Public Vehicle	2 (6%)	1 (3%)	3 (9%)	
	Relative House	1 (3%)	0 (0%)	1 (3%)	
	School	3 (9%)	1 (3%)	4 (13%)	
	Social	3 (9%)	0 (0%)	3 (9%)	
	Multiple occasion	4 (13%)	2 (6%)	6 (19%)	
Educational/ Intervention	Special School	4 (13%)	2 (07%)	6 (19%)	χ2 = .708 df = 4 p = 2.149 (NS)
	School	3 (3%)	0 (7%)	3 (9%)	
	Home	12 (38%)	2 (3%)	14 (44%)	
	Organisation	6 (19%)	2	8 (25%)	
	Other	1 (3%)	0	1 (3%)	
Primary Caregiver	Mother	13 (41%)	1 (12%)	14 (44%)	χ2 = .416 df = 4 p = 3.925 (NS)
	Father	2 (6%)	0 (1%)	2 (6%)	
	Both mutual	8 (25%)	3 (12%)	11 (34%)	
	Grandparent	2 (6%)	1 (0%)	3 (9%)	
	Other	1 (3%)	1 (0%)	2 (6%)	

NS= Not Significant

Table 3: QOL according to the Socio-Demographic Variables of Parents

Socio-demographic Variables		Mean ±SD	F	Sig.
Occupation	Unemployed (10)	48.10±6.790	.866	.603
	Government Job (6)	52.50±5.128		
	Private Business (8)	50.38±9.841		
	Freelance (3)	46.67±4.041		
	Wage Worker (4)	48.50±4.123		
	Homemaker (1)	59.00±.		
Caste/ Ethnicity	Brahmin (12)	50.25±8.368	.925	.553
	Chhetri (8)	48.00±2.507		
	Tamang (2)	55.50±.		
	Newar (5)	48.80±5.762		
	Magar (1)	59.00±.		
	Gurung (1)	54.00±.		
	Kirat (1)	54.00±.		
	Others (2)	42.50±14.849		
SES	High Middle (2)	54.00±.	.710	.739
	Middle (26)	50.27±6.010		
	Low Middle (2)	38.00±14.142		
	Low (3)	51.67±6.658		
Residence	Kathmandu Valley (16)	50.00±7.763	1.629	.169
	Out of Valley (16)	49.50±6.314		
Family Type	Nuclear (20)	49.85±6.385	.929	.550
	Joint (12)	49.58±8.140		
Training on MD	Trained (8)	48.50±9.798	.729	.722
	Untrained (24)	50.17±5.954		
Health related Problems	Illness (5)	47.40±12.280	.981	.508
	No Illness (27)	50.19±5.778		
Support for primary Caregiver	No support (2)	46.50±2.121	1.027	.473
	Spouse (21)	48.33±7.234		
	Grandparents (8)	54.50±5.425		
	Friends/Relatives (1)	48.00±.		

Table 4: Domains of QOL according the Socio-Demographic Variables of Children

Socio-demographic Variables		Physical Health		Psychological Health		Social Relationships		Environmental Health	
		Mean ±SD	F	Mean ±SD	F	Mean ±SD	F	Mean ±SD	F
Place of Delivery	Home delivery (9)	11.89 ±4.256	1.205 .341	11.93 ±2.093	3.012 .016	13.78 ±2.000	.327 .916	12.11 ±1.269	2.511 .035
	Hospital (23)	11.57 ±4.551		12.19 ±2.276		13.62 ±2.200		12.26 ±1.637	
Primary Caregiver	Mother (14)	8.50 ±9.192	.785 .632	10.33 ±2.357	3.319 .010	12.67 ±2.828	1.094 .393	11.00 ±.707	.906 .552
	Father (2)	12.07 ±4.615		11.83 ±2.825		13.81 ±2.374		12.07 ±1.542	
	Both mutual (11)	11.82 ±3.545		12.67 ±1.366		13.45 ±2.187		12.14 ±1.583	
	Grand parent (3)	10.33 ±6.429		12.67 ±1.764		14.67 ±1.333		13.17±1.443	
	Other (2)	13.00 ±.000		12.00 ±1.886		13.33 ±.000		13.50 ±1.414	

Table 5: Domains of QOL and Socio-Demographic Variables of Parents

Socio-demographic Variables		Physical Health		Psychological Health		Social Relationships		Environmental Health	
		Mean ±SD	F	Mean ± SD	F	Mean ± SD	F	Mean ± SD	F
Age	20-29 (4)	10.75 ±6.13	1.062 .427	12.00 ±.544	.486 .880	14.33 ±1.277	.426 .854	12.88 ±1.548	.426 .854
	30-39 (12)	13.67 ±1.969		12.39 ±1.763		13.78 ±2.564		12.71 ±1.499	
	40-49 (9)	9.00 ±5.339		11.30 ±3.576		13.19 ±2.155		11.44 ±1.509	
	50-59 (6)	11.83 ±4.401		12.78 ±.655		13.33 ±1.687		11.83 ±1.438	
	60-69 (1)	14.00 ±.		12.67 ±.		16.00 ±.		13.00 ±.	
Sex	Fathers (17)	11.29 ±4.398	1.067 .423	12.94 ±1.029	1.497 .209	14.04 ±2.217	.603 .726	12.62 ±1.463	.603 .726
	Mothers (15)	12.07 ±4.527		11.18 ±2.774		13.24 ±1.982		11.77 ±1.510	
Edu-cation	Illiterate (4)	11.00 ±6.055	.351 .946	11.83 ±2.203	1.791 .125	14.33 ±2.524	1.241 .319	11.75 ±.957	1.241 .319
	Primary Level (7)	11.00 ±4.655		10.33 ±3.426		13.14 ±2.098		11.21 ±1.890	
	Secon-dary Level (7)	13.14 ±2.193		12.38 ±1.433		12.76 ±1.301		11.57 ±1.305	
	Higher Secondary (8)	10.75 ±4.921		12.75 ±1.445		13.83 ±1.222		12.81 ±.961	
	Bachelor Degree (2)	15.001.414		13.67 ±1.414		14.00 ±6.600		13.50 ±1.414	
	Master Degree (4)	11.00 ±6.055		13.00 ±.667		15.00 ±2.000		13.75 ±.957	
		11.66 ±4.404		12.11 ±2.196		13.67 ±2.115		12.22 ±1524	
Occupation	Govern-ment Job (6)	11.00 ±4.648	.437 .900	12.67 ±.730	2.479 .038	14.89 ±2.446	.827 .560	13.67 ±1.080	.827 .560
	Private Business (8)	12.63 ±4.955		11.96 ±3.731		13.83 ±1.877		12.06 ±1.591	
	Freelance (3)	10.00 ±6.083		11.56 ±1.388		14.22 ±.770		11.33 ±.577	
	Wage Worker (4)	11.75 ±.957		10.83 ±.638		13.33 ±1.886		12.13 ±1.974	
	Home-maker (1)	11.73 ±4.756		12.55 ±1.809		12.85 ±.2.330		11.8 ±1.383	

Table 6: Domains of Coping Strategies according to the Socio-Demographic Variables of Parents

Socio-demographic Variables		Problem Focused		Emotion Focused		Avoidant Coping		Social Supported	
		Mean ±SD	F	Mean ± SD	F	Mean ± SD	F	Mean ± SD	F
Age	20-29 (4)	19.25 ±3.862	1.698 .146	21.50 ±3.000	1.214 .348	12.75 ±7.042	1.148 .388	17.00 ±3.559	1.315 .287
	30-39(12)	18.92 ±3.965		22.00 ±5.292		13.83 ±4.218		16.50 ±3.778	
	40-49 (9)	17.33 ±2.915		23.00 ±4.743		12.33 ±4.690		14.33 ±3.162	
	50-59 (6)	18.67 ±1.506		21.00 ±3.578		13.17 ±2.401		15.00 ±2.098	
	60-69 (1)	14.00±.		18.00±.		17.00±.		13.00±.	
Sex	Fathers (17)	19.24 ±3.231	.611 .808	22.35 ±4.471	1.618 .172	14.29 ±4.511	1.461 .227	16.29 ±2.910	1.220 .338
	Mothers (15)	17.27 ±3.105		21.40 ±4.501		12.07 ±3.882		14.73 ±3.615	
Edu-cation	Illiterate (4)	18.50 ±2.887	.719 .717	26.00 ±4.320	.682 .763	14.25 ±5.965	.630 .806	15.00 ±4.320	.735 .703
	Primary Level (7)	17.43 ±3.780		22.14 ±4.180		14.43 ±6.399		16.57 ±4.198	
	Secondary Level (7)	17.57 ±2.992		19.57 ±5.855		12.00 ±2.517		14.29 ±2.928	
	Higher Secon-dary (8)	18.38 ±2.615		21.13 ±3.182		13.50 ±3.817		15.38 ±2.387	
	Bachelor's Degree (2)	24.00 ±.000		26.00 ±.000		12.00 ±4.243		19.00 ±2.828	
	Master's Degree (4)	18.00 ±3.916		21.00 ±2.944		12.50 ±3.416		15.25 ±3.304	
Occu-pation	Unem-ployed (10)	18.50 ±2.915	. 606 .811	22.10 ±3.446	2.574 .033	14.90 ±4.533	1.571 .187	15.50 ±3.598	685 .746
	Govern-ment Job (6)	18.83 ±3.869		19.50 ±3.564		12.67 ±3.141		16.00 ±3.464	
	Private Business (8)	19.00 ±2.449		23.38 ±4.627		12.25 ±5.230		15.38 ±2.825	
	Freelance (3)	17.33 ±4.509		22.33 ±3.055		11.67 ±2.082		14.33 ±1.155	
	Wage Worker (4)	17.25 ±4.992		20.50 ±7.853		11.75 ±4.272		16.75 ±5.439	
	Home-maker (1)	15.00±.		27.00±.		19.00±.		14.00±.	
Religion	Hindu (26)	18.35 ±3.322	. 561 .847	21.38 ±4.337	3.855 .005	13.69 ±4.361	.258 .993	15.62 ±2.886	. 761 .681
	Buddhist (4)	18.25 ±4.272		23.50 ±4.359		12.00 ±4.690		15.50 ±6.557	
	Christian (1)	17.00±.		21.00±.		9.00±.		15.00±.	
	Others (1)	19.00±.		30.00±.		11.00±.		15.00±.	
Health related Problem	Illness (5)	16.20 ±2.280	3.132 .013	20.00 ±4.301	3.177 .013	14.40 ±4.561	2.201 .062	13.00 ±1.581	. 441 .925
	No Illness (27)	18.70 ±3.314		22.26 ±4.451		13.04 ±4.319		16.04 ±3.334	

Table 7: Domains of Coping Strategies according the Socio-demographic Variables of Children

Socio-demographic Variables		Problem Focused		Emotion Focused		Avoidant Coping		Social Supported Coping	
		Mean ±SD	F	Mean ±SD	F	Mean ±SD	F	Mean ±SD	F
Sex	Male Child (26)	18.50 ±3.524	.522 .875	21.69 ±4.389	2.338 .049	13.23 ±4.292	.781 .676	15.54 ±3.501	1.033 .460
	Female Child (6)	17.50 ±1.871		22.83 ±4.956		13.33 ±4.803		15.67 ±2.503	
Age of DMD Diagnosis	0-3 (8)	17.13 ±1.458	1.443 .230	20.63 ±2.973	1.312 .294	11.38 ±3.204	2.823 .022	14.63 ±2.560	2.628 .029
	4-7 (13)	19.38 ±3.501		22.38 ±5.606		13.00 ±3.873		16.38 ±3.731	
	8-11 (10)	18.20 ±3.853		21.80 ±3.795		14.50 ±5.233		15.40 ±3.438	
	12+ (1)	15.00±.		27.00±.		19.00±.		14.00±.	
Trained on Toileting	Trained (18)	18.28 ±3.878	3.576 .007	22.22 ±4.772	.551 .867	13.33 ±4.627	.976 .512	16.00 ±3.926	.585 .828
	Untrained (14)	18.36 ±2.437		21.50 ±4.109		13.14 ±4.036		15.00 ±2.287	

Table 8: Correlation between QOL and Coping Strategies and its Domains

	QOL	CS	Phy.H	Psy.H	SR	EH	PFC	EFC	AC	SSC
Quality of Life (QOL)	1									
Coping Strategies (CS)	**.389***	1								
Physical Health (Phy.H)	.754**	.343	1							
Psychological Health (Psy.H)	.590**	**.434***	.444*	1						
Social Relationships (SR)	.481**	.237	.042	.142	1					
Environmental Health (EH)	.570**	.132	.148	.492**	.481**	1				
Problem Focused Coping (PFC)	.204	.704**	.113	**.355***	.200	.318	1			
Emotional Focused Coping (EFC)	**.475****	.791**	**.386***	.235	**.372***	.153	.505**	1		
Avoidant Coping (AC)	.170	.491**	.196	**.443***	.044	-.030	.229	.031	1	
Social Supported Coping (SSC)	.216	.786**	.168	.276	.134	.180	.638**	.514**	.246	1

***. Correlation is significant at the 0.01 level. (2-tailed)*

**. Correlation is significant at the 0.05 level. (2-tailed)*

DISCUSSION:

When the child is diagnosed with DMD, parents begin a new life with their affected child. In this study 53% (17) fathers slightly outnumbered 47% (15)mothers, probably because sample were drawn from the MDF-Nepal annual health camp where children were more likely to be accompanied by their fathers. There were equal number of participation within valley and out of valley (n=16, 50%). 63% (20) parents had nuclear family, which also explains why family support may have been less and coping was difficult, especially when the primary caretakers were mothers only, which also impacted their quality of life.

66% (21) parents got support from their spouse while raising their children whereas 25% (8) parents received support from grandparents as well. 44% (14) primary caregivers were mainly the mothers in contrast only 6% (6) were fathers but 34% (11) parents were raising their DMD children mutually and 3 (9%) primary caregivers were grandparents. The studies undertaken in recent years regarding care in the management of various chronic illnesses in children and adolescents indicate that it is the mothers who are the main people involved in the care process.[20] It may be perceived that there is a certain variability in the mothers' adaptation to their children's chronic conditions, given that the majority feel themselves to be vulnerable, requiring support in various instances.[22] Caregiving aspects include providing emotional and social support, assistance with basic and instrumental daily activities, and administration and organization of formal healthcare. The caregivers' quality of life scores tend to vary in accordance with the content of the information received, specific aspects of each illness and the personal resources of the caregivers. In the perception of absence of maternal self-efficacy, low levels of quality of life and mental health are established. [23-25]This study indicated 75% (24) parents were untrained about DMD and 97% of the parents had below average level of Quality of Life (QoL).

The lower scores on QoL could also be an expression of parents due to their added expectations from the health camp. The primary caregivers were mainly the mothers but parents raising their children mutually had better QOL compared to others. This also emphasizes the need and importance of family and social support and most significantly the co-support of both the parents in rearing a child with disability. A review study reports that taking care of DMD children can have significant effects on caregivers, leading to a lower health-related quality of life, poor sleep quality, depression, pain, stress, sexual dysfunction, and lower self-esteem. Accordingly, caregiving can also have a considerable negative impact on work life and productivity. [26]

As in other studies there were higher number of male DMD children in this study too; i.e. 81% (26) male children with DMD were almost four times more compared to 19%(6) female children .[27] 72% (23) were hospital born and 41%(13) were diagnosed at 4-7 years. 47% (15) were 1st born, followed by 44% (14) second birth order. 60% of children had one sibling. 56% (18) children were trained and managed their self-care and toileting. 53% (17) children were calm, but 22% (7) were aggressive and 16% (5) were hyperactive. Children with disabilities have indicated to demonstrate emotional and behavioral problems.[28]In this study, 44% (14) DMD children stayed home, whereas 25% (8) came to the organization and 19% (6) went to special school. It was found that children were devoid from special school education. Special children having DMD benefit from special education and need specialized care and do not have to be home bound.[29]

Parents with government job had better psychological health compared to the parents with other professions. Parents of DMD children delivered at hospital had better psychological health and environmental health compared to children delivered at home. Parents not having health related problems and government jobholders mainly used emotion-focused coping. On the other hand, there were significant differences among the parents with the children diagnosed after 12years, where they used avoidant coping and social supported coping. Similarly, parents whose children were not toilet trained used problem-focused coping. When parents coped better, their Quality of life was also better.

When parents used problem focused coping or avoidant coping then their psychological health was also found to be good though their QoL was generally low. Whereas when they were physically healthy, they used emotion focused coping strategies and maintained good social relationships. It has been found that mothers and fathers may adopt different coping strategies. Parents who use avoidance coping strategies tend to be more stressed and therefore, are prone to poor QOL levels.[30] Researches indicate that there is a general tendency for young adults to use more problem-focused coping strategies and middle-aged adults to use emotion-focused coping strategies.[14]This study delivers several implications for parents and professionals taking care of DMD children. Medical, educational, and other professionals can also learn and benefit from the lived experience of parents, their quality of life and their coping with DMD on a daily basis.

CONCLUSION:

Though the study sample was less the study findings cannot be simply generalized, however, the study findings will create a perspective towards understanding the QOL and coping strategies of parents of children with Muscular Dystrophy and related factors affecting them and their children. This study findings also emphasizes the fact that when parents accept their feelings and focus on their self- care, talk to people close to them and share their woes and ask for help and take out time to enjoy their time with the child then coping is better. Further research including a larger sample is recommended, to further explain changes in QOL over time and to assess the impact of targeted interventions to improve consequences. This study also highlights the importance of continued efforts of coordination between organizations working in DMD and parents handling children with DMD. While we anticipate the discovery of molecular genetic therapies for correction of the physiologic defect, continuation and optimization of the comprehensive treatment strategies for the improvement of physical and psychosocial conditions of children and adolescents with DMD has to be emphasized. Simultaneously, factors promoting parents and caretakers physical and psychological health has to be promoted which will have positive impact and improve QOL and coping of parents and caretakers.

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