

ORIGINAL RESEARCH**Assessment of stress level of primary care giver of disabled children of age 6-15 years: A case control study****¹Dr. Kulwinder Kaur, ²Dr. Sanjeev Mahajan, ³Dr. Jasleen Kaur, ⁴Dr. Preeti Padda, ⁵Dr. Shayam Sunder Deepti**¹Junior Resident, ²Professor and Head, ^{3,4}Associate Professor, ⁵Professor, Department of Community Medicine, GMC, Amritsar, Punjab, India**Corresponding author**

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Abstract**Introduction:** Children are the hope of their parents and simultaneously important assets for future development of any nation. Children with disability may have special needs particularly regarding health and education. Taking care of these disabled children may enhance the stress level of the primary care giver.**Material and methods:** The present case control study was conducted in rural field practice areas of Department of Community Medicine, GMC Amritsar among disabled and normal children aged between 6-15 years along with their primary care givers. A house to house survey of villages under Majitha block was conducted. A total 300 children and their primary care givers were included (100 disabled children and 200 controls). A one to one interviews, information regarding socio-demographic profile; personal details of child and their primary care giver were recorded on a structured proforma.**Results:** Prevalence of childhood disability among 6-15 years age group came out to be 0.92%. According to parental stress scale, 71% of primary care givers of cases had high parental stress. Primary care givers of cases who studied up to primary or more had less stress as compared to those who were illiterate. Higher parental stress was observed among primary care givers of cases with 61-100% disability than those with 0-60% disability.**Conclusion:** Parenting of disabled child can have profound effects on the parents and family. Presently health providers are focusing only on the wellbeing of children with disability; their caregivers are ignored to a large extent.**Keywords:** stress level, disabled children, disability status**Introduction**Childhood is an essential period of life, requiring an engaging environment and nurturing care to support and facilitate development.¹ Disability in childhood can have a lifelong impact on a person's physical, mental and emotional health, as well as their social situation. Children with disabilities experience ableism, stigma and discrimination in all facets of life, which affects their physical and mental health.

In India, there are about 4,733,765 children in the age group of 0–19 years with disability making it to about 0.3% of the whole population. Poor socioeconomic status increases the risk of a child having impairment, e.g. increased risk of low-birth weight babies among low-income families. Parents of children usually experience higher stress, anxiety, and depressive

symptoms compared to parents of typically developing children.^{2,3} All these lead to a burden in caregivers which is commonly known as caregivers' burden. Caregiver burden is defined as the stress and other psychological symptoms experienced by family members and other non-professional caregivers in response to looking after individuals with mental or physical disabilities, disorders and diseases.⁴ Children with disability may have special needs particularly regarding health and education and may need to negotiate significant social and environmental barrier in order to fully participate in everyday life. Taking care of these disable children may enhance the stress level of the primary care giver. Very few studies have been conducted on childhood disability. Therefore, the present study is aimed to assess the level of disability of these children and compare the parental stress of primary care givers of disabled with healthy children.

Materials and methods

The present case control study was conducted in rural field practice areas of Department of Community Medicine, GMC Amritsar among disabled and normal children aged between 6-15 years along with their primary care givers. A house to house survey of villages under Majitha block was conducted. For selection of cases Non Probability consecutive sampling technique was used whereas for selection of control (2 times that of cases) simple random sampling technique was used. A total of 300 children and their primary care givers were included. Case was defined as any disabled child of either sex (long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others) with locomotor disability, visual impairment, hearing impairment, chronic neurological conditions, person affected with blood related disorder, mental illness or developmental disorder. Controls were selected from the same area as that of cases after matching for both age (± 1 year) and sex. Children with any chronic ailment/ disease (e.g. type 1 diabetes, active TB, leukemia or any childhood cancer etc.) were excluded. Children who were residing in the same household as that of disabled child were also excluded from the study. Primary care giver of both gender aged more than 18 years and those who gave a written informed consent were included. A one to one interview with child and primary care giver was conducted for collecting information regarding socio-demographic profile, personal details were recorded on a structured performa for both cases and controls. Additional information regarding disability was recorded 1) Level of disability in percentage was assessed as per guideline given in gazette of India, 2018 after examination of the child or as per the disability certificate (if available) 2) Use of rehabilitation services. Parental stress scale was used for assessment of parental stress. Each question was rated on a five-point scale where 1= Strongly Disagree; 2=Disagree; 3= Undecided; 4= Agree; 5=Strongly Agree. Chi square/t-test was applied for assessment of association and odd's ratio was calculated for strength of association.

Results

A total 300 children and their primary care givers were included (100 disabled children and 200 controls).

Table 1: Distribution of cases and controls according to their socio-demographic profile (N=300)

Variable	Cases(n=100)	Controls (n=200)	Total (N=300)
Gender			
Male	60 (60)	120 (60)	180(60)
Female	40 (40)	80 (40)	120(40)
Type of family			
Nuclear	69(69)	117 (59)	186(62)

Joint	31 (31)	83 (41)	114(38)
Socioeconomic status			
Social class I,II,III	20 (20)	53(26)	73 (24)
Social class IV,V	80 (80)	147 (74)	227 (76)
Schooling status of children			
Currently going to school	69 (69)	195 (98)	264 (88)
Never gone to school	31 (31)	5 (02)	36 (12)
OR= 17.52(06.55- 46.85) p value= <0.001*			

(Figure in parenthesis are percentages)

Mean age of cases was 11±3 and of controls 11±2.6. Males were higher in number (60%) and majority (62%) of study participants resided in nuclear families. According to BG Prasad classification of socio economic status of study participants, higher proportion 80% of cases and 74% of controls belonged to social class IV,V (table 1).Cases had17.52 (06.55- 46.85) times higher odds of never gone to school/dropout as compared to controls. This difference was found to be highly significant (table 1).

Table 2: Distribution of cases and controls according to their primary care giver (N=300)

Variables	Cases (n =100)	Controls (n =200)	Total (N=300)
Main primary care giver of child			
Father	1 (01)	29 (15)	30 (10)
Mother	95 (95)	154 (77)	249(83)
Others (Grandmother, Maternal aunt, Paternal aunt)	4 (04)	17 (08)	21(07)
Education status of primary care giver			
Illiterate	55 (55)	59 (30)	114(38)
≥ Primary school	45 (45)	141 (70)	186(62)
Occupation of primary care giver			
Unemployed	53 (53)	104 (52)	157(52)
Employed	47(47)	96 (32)	143(48)

(Figures in parentheses are percentages)

Among cases majority i.e. 95% of participants had mothers as primary care giver and only 1 (1%) had father as primary care giver. Among controls 77% participants were taken care by mothers and 15% by fathers. Among cases the illiterate primary care givers were 55%, while 45% were educated up to primary or more. As far as occupation was concerned employed primary care givers were 47%, while 53% were unemployed (table 2).

Mean Parental stress score of cases (60.83±06.38) was higher as compared to controls (40.00±08.00). It means primary care of cases had higher parental stress as compared to controls. The difference was found to be highly significant. Full range of scores (29-70) were divided into 3 equal sections that is mild, moderate and high parental score in ascending order and observations are described in table 3.

Table 3: Association of disability with parental stress of primary care givers (N=300)

PSS (PS score)	Cases (n=100)	Controls (n=200)
Mild PS (29-43)	5(5)	172(86)
Moderate PS (44-57)	24(24)	18(9)
High PS(58-70)	71(71)	10(5)
$\chi^2 = 159.03, p = < 0.001^*, df = 2$		

*p-value < 0.001 was considered highly significant

According to parental stress scale, 71% of primary care givers of cases had high parental stress followed by 24% moderate and 5% had low parental stress. Among controls, 86% of primary care givers had low parental stress while 9% moderate and only 5% had high parental stress. The difference was found to be highly significant (table 3).

Table 4: Association between socio demographic profile of cases with parental stress of primary care givers (PSS) (N=100)

Variables		PS score	t value	P value
Gender	Male (n=60)	61.32±05.90	0.934	0.353
	Female (n=40)	60.10±07.04		
Type of family	Nuclear (n=69)	61.00±06.70	0.396	0.693
	Joint (n=31)	60.45±05.66		
Socioeconomic status	I,II,III (n=20)	62.70±03.84	1.475	0.143
	IV,V (n=80)	60.36±06.80		
Schooling status	Currently going to school (N=69)	59.66±6.97	-2.599	0.011*
	Never gone to school (N=29)	63.24±3.79		

*p-value < 0.05 was considered significant

Primary care giver of male children with disability, residing in nuclear families and belonging to socioeconomic status (I,II,III) had higher parental stress. However, no significant difference was found (table 4). On the other hand, significantly higher parental stress was observed among primary care givers of cases who had never gone to school than those of currently going to school (table 4).

Table 5: Association between type of disability of cases with parental stress of primary care givers (PSS) (N=100)

Variables		PS score	t value	P value
Kind of disability	Congenital(n=80)	61.17 ± 06.41	1.083	0.281
	Acquired (n=20)	59.45 ± 06.17		
Type of disability	Temporary(n=28)	59.05 ± 06.71	-1.305	0.195
	Permanent (n=72)	61.34± 06.21		
Number of disability	Single (N=32)	59.34± 07.35	-1.611	0.110
	Multiple (N=68)	61.52±05.79		

Out of total cases, large number of children i.e. 80 had congenital disability and 20 had acquired disability. Similarly majority of the cases 72 had permanent disability while 28 of cases had temporary disability. 68 had multiple disabilities while 32 of cases suffered from single disability. Primary care givers of cases having congenital, permanent and multiple disabilities had more parental stress. However, difference was not found to be significant (table 5).

Table 6: Association between current status of disability of cases with parental stress of primary care givers (PSS) (N=100)

Variables		PS score	t value	P value
Current status of disability	Improved/stable(n=54)	59.27±07.15	-2.721	0.008*
	Deteriorate (n=46)	62.65±04.78		
Level of disability	≤60% (n=52)	59.36±06.92	-2.450	0.016*
	61-100% (n=48)	62.41±05.35		
Use of rehabilitation services	Yes (n=44)	59.95±07.65	-1.220	0.225
	No (n=56)	61.51±05.12		

* p-value <0.05 was considered significant

According to the current status of disability from the time of diagnosis, almost half 46% had deteriorate, 54% had stable status/ improved status. 52% cases had disability $\leq 60\%$ whereas 48% had disability 60-100%. Study participants of cases whose condition had deteriorated and disability more than 60% had more parental stress which was statistically significant also. As far as use of rehabilitation was concerned, 44% had used some sort of rehabilitation and their primary care givers had less stress as compared to those who did not use any rehabilitative measures (table 6).

Table 7: Association between education and employment status of primary care givers (PCG) of cases with their parental stress (PSS) (N=100)

Variables		PS score	t value	P value
Education of PCG	Illiterate (n=55)	61.96±05.10	1.994	0.049*
	\geq primary (n=45)	59.44±07.47		
Occupation of PCG	Employed (n=47)	62.12 ±04.74	-1.943	0.055
	Unemployed (n=53)	59.67±07.39		

* p-value <0.05 was considered significant

Primary care givers of cases who studied up to primary or more had significantly less (59.44±07.47) stress as compared to those who were illiterate (61.96±05.10). As far as occupation of primary care givers is concerned, it was observed that employed primary care givers of cases had more stress (62.12 ± 04.74) than the ones who were unemployed (59.67±07.39) and living at home (table 7).

Discussion

Children with disability are a wellspring of interminable stress to the caregivers, and it can influence them adversely in numerous ways. Mean age of cases was 11±3 and of controls 11±2.6. Males were higher in number (60%) in comparison to females (40%) (table1). Similar result were observed in a study conducted in rural area of Karnataka by *Arasu S*, the mean age of children was 11.43 years and 56% were males.⁵ Study done by *Fentanew M et al* in Northwest Ethiopia showed most of the children with disabilities 169 (54.2%) were males.⁶ In present study, among cases majority 95% of participants had mothers as primary care giver and only 1% had father as primary care giver. Among controls 77% participants were taken care by mother and only 15% had fathers as primary care giver (table 2). Similar study *Maridal HK et al*, done on caregivers of children with neurodevelopment disorders showed that a total of 63 primary caregivers were interviewed, all of them women: 60 (95%) were biological mothers.⁷

Mean Parental stress score of cases (60.83±06.38) was higher as compared to controls (40.00±08.00). It means primary care of cases had higher parental stress as compared to controls. The difference was found to be highly significant. Similar study conducted by *Sinha D et al* in Mumbai on parents of children with autism and having specific learning disorder found parental stress to be significantly higher in parents of disabled children.⁸ In our study, according to parental stress scale, 71% of primary care givers of cases and 5% of controls had high parental stress. The difference was found to be statistically significant (table 3).

In this study it was observed that primary care giver of male children with disability had higher(61.31±5.90) parental stress as compared to female children with disability(60.1±7.04). However, difference was not found to be significant (table 4). *Gupta VB et al* observed that parents of children with disability showed higher parental stress amongst study participants of male children with disability than study participants of female children with disability. However, the difference was not found to be significant statistically.⁹

In present study, trend of living in nuclear families was higher both in cases and controls(table 1). Similar study done by *Majumdar R.* on caregivers of children with or without disabilities

observed that more children were residing in nuclear families as compared to joint families in both case and control group.⁴ Primary care givers of cases, living in nuclear families had more parental stress than those of joint families. Though, this difference was not found to be significant statistically (table 4). This can be attributed to the fact that in joint family more people are available to look after the child. In a nuclear family setup, mother has to do the household duties also which can lead to decreased attention and care to the child.

In this study, according to BG Prasad classification of socio economic status of study participants, higher proportion 80% of cases and 74% of controls belonged to social class IV,V (table 1). Census 2011 reported there is evidence (for instance from the TEACH survey) that disabled children are more likely to be in poorer households.¹⁰ Primary care givers of cases belonging to socioeconomic status I, II and III had more parental stress than of socioeconomic status IV and V. However, no significant difference was seen between SES and level of stress in caregivers (table 4).

In present study it was observed that 69% cases were currently going to school which was less number against 98% of controls (table 1). The Census 2011 showed that 61% of the disabled children aged 5-19 years are attending educational institution.¹¹ Significantly higher parental stress was observed among primary care givers of cases who had never gone to school than those of currently going to school (table 4). This may be due to the fact that children that go to school, spend their time in school under teacher's supervision so parents get some free time for themselves and burden on them is thus decreased.

In our study, 55% primary care givers of cases and 30% of controls were illiterate (table 2). Similar study done by Kriti K et al on caregivers of CP children that out of 100 caregivers, educational level of caregivers was noted and out of all, 51 were illiterate, 43 went to high school/intermediate, and 6 were graduate.¹² This study observed that primary care givers of cases who were studied up to primary or more had lesser stress as compared to those who were illiterate. This difference was found to be statistically significant (table 7). Various studies showed the relationship between maternal education and parental stress is also curvilinear that mothers with low education experiencing higher levels of parental stress than mothers with intermediate education.^{13,14}

Among cases i.e 53% of primary care giver and 52% among controls were found to be unemployed (table 2). Study conducted by Arasu S et al in Karnataka observed most of the primary care givers are not gainfully employed (65%) while the rest are involved in farming or unskilled work.¹⁵ Present study observed that employed primary care givers of cases had more stress than the ones who were unemployed (table 7). Gupta VB et al study done in India on care givers of disabled children showed that parents engaged in more prestigious and gainful occupations had more parenting stress, perhaps because of a wider gap between their expectations and reality.¹⁶

Significantly higher parental stress among primary care givers of cases with 61-100% disability and whose condition had deteriorated with time. This may be due to the fact that children with higher disability or deteriorated condition require extra care, which leads to more stress on the parents.

Primary care givers of children who used rehabilitative measures had less stress as compared to those who did not use rehabilitative measures. With use of rehabilitation services child is able to do his day to day activity and can explore the environment and other sources of learning for the physical-motor, cognitive, social and psychological development. Study conducted in northwest Ethiopia showed, the number of services delivered for children with disabilities was significantly correlated to caregiver satisfaction.⁶

Conclusion

Living with a disabled child can have profound effects on parents and family members. Primary care givers of cases having congenital, permanent, 61-100% level with deteriorate status and multiple disabilities had more parental stress. Presently health providers are focusing on the wellbeing of children with disability; their caregivers are ignored to a large extent.

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