

# Burden of Care among Mothers Having Children with Down Syndrome

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## ABSTRACT

**Background:** Down syndrome is the most common chromosomal disorder associated with mental retardation. Parents who are the primary caregivers of a child with a disability face numerous challenges in their day-to-day life. The objective of the study was to find out the burden of care among mothers having children with down syndrome.

**Methods:** A descriptive cross-sectional study was carried out among 96 mothers having down syndrome children enrolled in the Down Syndrome Society, Nepal. Purposive Sampling technique was adopted for data collection. The Modified Caregiver Strain Index tool was used to collect data through interview. Data were collected from June 14, 2021 to August 1, 2021, which was analyzed by using descriptive and inferential statistics.

**Results:** Findings revealed that majority of the mothers (77.1%) had high level of burden of care. Majority (89.6%) of the mothers involved in the study were always overwhelmed about their child's conditions. More than half (55.2%) of the mothers were always financially strained in care giving, 57.3% had always done work adjustments and 60.4% of mothers always had emotional adjustments to be made. Similarly, 53.1% participants always felt that care giving was a physical strain. Burden of care was significantly associated with the age of delivery (p value= 0.008).

**Conclusions:** The study concludes that mothers having children with down syndrome tend to have high level of burden of care and it is associated with the age at delivery. Therefore, health care providers including concerned authority are recommended to conduct different programs to support the caregivers in order to reduce their burden as well as to raise awareness program related to preventive measures of down syndrome in community.

**Keywords:** Burden of care; down syndrome; mothers

## INTRODUCTION

Down syndrome (DS) is a common chromosomal disorder associated with mental retardation<sup>1</sup>, which can involve delayed growth, additional health problems.<sup>2</sup> Parents of children with down syndrome have higher levels of parenting stress.<sup>3</sup> Each year approximately 6000 children are born with Down Syndrome.<sup>4</sup> Down syndrome is between 1 in 1000 to 1 in 1100 live births world wide.<sup>5</sup> Down syndrome threatens the psychological wellbeing of all other family members, especially the parents.<sup>6</sup> Generally taking care of these disabled children increases stress and family burden on mothers.<sup>7</sup>

Symptoms of anxiety and depression are reported by caregivers of individuals with intellectual disabilities.<sup>8</sup> Research has also shown that children needed support, financial assistance, and engagement in their education

as they grew older.<sup>9</sup>

It is crucial to understand the burden faced by mothers in order to create appropriate programme to minimize the burden. The findings of the study would provide baseline information about the burden of care among mothers having children with Down syndrome.

## METHODS

A descriptive cross-sectional study was carried out to assess the burden of care among mothers having children with Down syndrome using purposive sampling technique. Sample size was calculated using Cochrane formula, considering the 94% prevalence of burden of care among mothers having down syndrome children study in india<sup>10</sup>. Thus select total of 96 mothers who had children diagnosed with down syndrome and who were

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registered in Down Syndrome Society Nepal, Kapurdhara Marg, Kathmandu, Nepal, willing to participate in this study.

Data were collected from the mothers through interview using the Modified Care Strain Index (MCSI) tool along with a section on sociodemographic characteristics. MCSI tool consisted of 13 items in a rating scale was used with a maximum score of 26 and minimum of zero. The level of caregiver strain increases with MCSI score. The Burden of care was divided as high burden and low burden. A high burden meant score equal to and more than mean score and low burden meant score less than mean score. There was at least one item on each of the following major domains: financial, physical, psychological, social, and personal domain. The translated Nepali version instrument was used which was already used by the authors in article<sup>12</sup>. The Nepali version instrument was pretested among similar mothers before using for the final study. Data were collected from June 14, 2021 to August 1, 2021.

Before data collection ethical approval for research proposal was taken from Nepal Health Research Council (NHRC) Kathmandu. Formal permission was obtained from the Down Syndrome Society, Kapurdhara Marg, Kathmandu, Nepal. An informed verbal consent was taken from mothers before starting interview, because of the lockdown due to Covid-19 pandemic. Data was collected by the researchers themselves and two trained research assistants. Only interested mothers were included in the study. Participants were explained that they can leave the study at any time if they want. Confidentiality of the participant was maintained by keeping information in such a way that only researcher could assess them and also assured that the information obtained would be used only for the research purpose only. Collected data were edited and coded. The coded data were analyzed by using Statistical Package for Social Science (SPSS) version 16. Descriptive statistics (frequency, percentage, mean, and standard deviation) and inferential statistics chi square test was used to measure the associations between influencing and study variables.

## RESULTS

Table 1 shows that around half of the mothers (49.0%) were of 41- 60 years of age with mean age  $\pm$  and SD (43.43  $\pm$  11.3). About two fifth (40.6%) belongs to Brahmin/ Chhetri ethnicity. Most (85.5%) of the mothers followed Hindu Religion, majority (71.9%) of them were

residing in urban area. More than half (57.3%) were living in a nuclear family. More than half (58.3%) of the respondents belonged to middle - class family and most (79.2%) of them had delivered their affected children within 35 years of age.

**Table 1. Socio- demographic Characteristics of Mothers (n=96).**

Characteristics	Frequency	Percent
<b>Age (in years)</b>		
$\leq 40$	43	44.8
41-60	47	49.0
Above 60	6	6.2
Mean Age $\pm$ SD	43.43 $\pm$ 11.3	
<b>Ethnicity</b>		
Brahmin/ Chhetri	39	40.6
Janajati	44	45.8
Madeshi	4	4.2
Dalit	9	9.4
<b>Religion</b>		
Hinduism	82	85.5
Buddhism	13	13.5
Muslim	1	1.0
<b>Residence Area</b>		
Rural	27	28.1
Urban	69	71.9
<b>Type of family</b>		
Nuclear	55	57.3
Joint	41	42.7
<b>Economic Status</b>		
High	1	1.1
Middle	56	58.3
Low	39	40.6
<b>Age at Delivery</b>		
$\leq 25$ years	34	35.4
26-35 years	42	43.8
$\geq 36$ years	20	20.8
Mean Age $\pm$ SD at Delivery	28.85 $\pm$ 7.15	

Table 2 represents that more than one third (36.8%) of the children with Down Syndrome were of age group 11-15 years. More than half (54.2%) were male and were diagnosed at the age of 4-5 years (36.8%). Around half (49%) had one sibling, few (2.1%) had other affected sibling. Nearly half (47.9%) were attending school and almost all (91.3%) of them were in special schools.

Table 2. Socio-Demographic Characteristics of Children with Down's Syndrome (n=96).

Characteristics	Frequency	Percent
<b>Age (in years)</b>		
Upto 5	8	8.4
6- 10	19	19.8
11-15	35	36.8
16-19	34	35.4
<b>Sex</b>		
Male	52	54.2
Female	44	45.8
<b>Age at diagnosis (years)</b>		
0-1	29	30.2
2-3	23	24.0
4-5	44	45.8
<b>Affected Sibling</b>		
Yes	2	2.1
No	94	97.9
<b>Attending School</b>		
Yes	46	47.9
No	50	52.1
<b>Type of School (n=46)</b>		
Normal School	4	8.7
Special School	42	91.3

Table 3 depicts that disturbed sleep was experienced sometimes by more than one third mothers (39.6%) included in the study. More than half (53.1%) of mothers felt care giving was always inconvenient less than half (42.7%) sometimes thought that care giving was physically straining, majority (60.4%) of the mothers always did emotional adjustments. Nearly one third (32.3%) mothers were always upset due to some behavior of children and half (50.0%) of the mothers were always upset to find that their child's health condition was getting worse due to Down Syndrome. More than half (57.3%) of the mothers always had to do work adjustments to care for their child with DS and more than half (55.2%) of the mothers always felt that care giving was financially straining. Most (89.6%) of the mothers always felt overwhelmed during care of child with DS.

Table 3. Modified Caregiver Strain Index Scoring of the Mothers (n=96).

Items	Always	Sometimes	Never
	No (%)	No (%)	No (%)
Sleep disturbance	36 (37.5)	38 (39.6)	22 (22.9)
Care giving is inconvenient	51 (53.1)	38 (39.6)	7 (7.3)
Care giving is a physical strain	34 (35.4)	41 (42.7)	21 (21.9)
Care giving is confining	38 (39.6)	46 (47.9)	12 (12.5)
There have been family adjustments	32 (33.3)	41 (42.7)	23 (24.0)
There have been changes in personal plans	39 (40.6)	13 (13.6)	44 (45.8)
There have been other demands at the same time	46 (47.9)	32 (33.3)	18 (18.8)
There have been emotional adjustments	58 (60.4)	38 (39.6)	-
Some behavior of the child is upsetting	31 (32.3)	31 (32.3)	34 (35.4)
It is upsetting to find the child's health condition has changed to be worse	48 (50.0)	29 (30.2)	19 (19.8)
There have been work adjustments	55 (57.3)	33 (34.4)	8 (8.3)
Care giving is a financial strain	53 (55.2)	19 (19.8)	24 (25.0)
Overwhelmed feeling	86 (89.6)	10 (10.4)	

Table 4 illustrates that majority (77.1%) of the mothers had high level of burden of care due to having children with Down Syndrome. The Mean care burden score was 12.7.

Table 4. Level of Care Burden among the Mothers (n=96).

Level of Burden	Number	Percent
High ( $\geq$ Mean Score)	74	77.1
Low ( $<$ Mean Score)	22	22.9

Table 5 presents that mothers level of burden was statistically significant with the age at the time of

delivery ( $p$  value= 0.008) but there was no significant association between mothers burden of care with other socio-demographic characteristics of the mother as  $p$  - value was greater than 0.05.

**Table 5. Association of Mothers' Level of Care Burden with Socio-Demographic Variables (n=96).**

Variables	Level of Burden*		Chi-Square Value	P-Value
	Low No (%)	High No (%)		
<b>Age of Mother</b>				
≤40 years	7(16.3)	36(83.7)	1.943	0.163
> 40 years	15(28.3)	38(71.7)		
<b>Ethnicity</b>				
Brahmin/Chhetri	10(25.6)	29(74.4)	0.276	0.599
Others <sup>1</sup>	12(21.1)	45(78.9)		
<b>Religion</b>				
Hinduism	19(23.2)	63(76.8)	0.021	0.886
Others <sup>2</sup>	3(21.4)	11(78.6)		
<b>Residence Area</b>				
Urban	17(24.6)	52(75.4)	0.411	0.521
Rural	5(18.5)	22(81.5)		
<b>Family Type</b>				
Nuclear	15(27.3)	40(72.7)	1.383	0.240
Joint	7(17.1)	34(82.9)		
<b>Education</b>				
Illiterate	8 (32.0)	17 (68.0)	1.579	0.209
Literate	14 (19.7)	57 (80.3)		
<b>Occupation</b>				
Home maker	12(20.3)	47(79.7)	0.831	0.362
Others <sup>3</sup>	12(32.4)	25(67.6)		
<b>Economic Status</b>				
Middle to high	15(26.3)	42(73.7)	0.918	0.338
Low	7(17.9)	32(82.1)		
<b>Age at Delivery</b>				
Upto 35 years	13(17.1)	63(82.9)	6.974	0.008
Above 35 years	9(45.0)	11(55.0)		

Level of Burden: Low (1-13 score), High (14-26 score); Others<sup>1</sup>: Janajati, Madhesi, Dalit; others<sup>2</sup>: Buddhism, Muslim; Others<sup>3</sup>: Agriculture, Business, Service, Home maker and agriculture. P value significance < 0.05

Table 6 depicts no significant association of mothers' burden of care with socio-demographic characteristics related to children as  $p$  - value was greater than 0.05.

**Table 6. Association between Mother's Burden of Care and Socio-Demographic Characteristics related to Children (n=96).**

Variables	Level of Burden		Chi-Square Value	p - Value
	Low No (%)	High No (%)		
<b>Age</b>				
≤15 years	3(11.1)	24(88.9)	2.964	0.085
>15 years	19(27.5)	50(72.5)		
<b>Sex</b>				
Male	10(19.2)	42(80.8)	0.873	0.350
Female	12(27.3)	32(72.7)		
<b>Birth order</b>				
First born	7(15.2)	39(84.8)	2.964	0.084
Consecutive born	15(30.0)	35(70.0)		
<b>Age at diagnosis</b>				
≤ 3 years	11(21.2)	41(78.8)	0.200	0.655
> 3 years	11(25.0)	33(75.0)		
<b>Number of Siblings</b>				
Upto 1	16(23.9)	51(76.1)	0.117	0.733
≥2	6(20.7)	23(79.3)		
<b>Present Health Problem</b>				
Yes	10(28.6)	25(71.4)	1.553	0.213
No	10(16.4)	51(83.6)		
<b>Attending School</b>				
Yes	13(28.3)	33(71.7)		
No	9(18.0)	41(82.0)	1.428	0.232

F= fisher exact test

## DISCUSSION

Present study revealed around half (49.0%) of the mothers were of 41- 60 years of age and more than half (57.3%) were living in a nuclear family. Most of them (76%) were literate. Majority (61.5%) were homemaker and more than half (58.3 %) were of middle-class family and less than half (43.8%) were having delivery of the affected child at the age of 26-35 years. This finding was consistent with the findings of the study conducted by Norizoan & Shamsuddin in Malaysia in which average age of respondents was 43.1 years (SD=7.6 years), almost all mothers (94.6%) were married, 57.1% had secondary

level education and 28.6% were working outside their home.<sup>10</sup> Regarding the age group of caregiver, older caregivers experienced higher burden of care.<sup>11</sup>

The findings of this study revealed that most of the mothers (89.6%) always felt overwhelmed during care of child with down syndrome, more than half of the mothers (60.4%) always did emotional adjustments; 57.3% mothers always had to do work adjustments to care for their child, 55.2% always felt that care giving was financially straining and 53.1% felt caregiving was inconvenient always. Consistent with this study's findings, another study, revealed that (52.6%) had exhaustion in mothers in comparison with their partners.<sup>12</sup>

Present study revealed that mother's level of burden was statistically significant to the age at the time of delivery ( $p$  value= 0.008) while no significant association of the level of caregiver burden, with other socio-demographic variables such as residents, occupation and education as revealed in a study conducted in Mangaluru, India.<sup>13</sup> Present study revealed no significant association between mother's burden of care with sociodemographic characteristics of children. In contrast to the findings of this study moderate and strong evidence of a positive correlation was revealed between the caregiver burden with the age of the child ( $r=0.245$ ,  $P=0.009$ ) and stress ( $r = 0.45$ ,  $P <0.001$ ) .<sup>13</sup>

The findings of this study revealed that most of the mothers (77.1%) had high level of burden of care having children with down syndrome. In contrast to this study, a cross-sectional study conducted in Mansoura, Egypt among 457 family primary care givers of down syndrome children found that more than half (51.9%) of care givers had none or little burden, 40.7% had mild to moderate burden and 7.4% had moderate to severe burden.<sup>14</sup> Similarly, in a study done in India, by Devi, D'mello & Rent, 50.9% of the parents reported mild-to-moderate burden and 26.8% reported moderate-to-severe burden.<sup>13</sup> Another study in India, reported that 40% of caregivers had moderate to severe burden.<sup>15</sup> This discrepancy of present study with the findings of previous studies may be due to different sample.

## CONCLUSIONS

The study concluded that mothers of down syndrome children in general experience high burden of care. Mothers feel overwhelmed due to the child condition. They also face financial constrain to care for the child.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest

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