



## Social stigma and psychological burden among caregivers of children with cerebral palsy

Noora Farhan Hassan al-Abedi

Faculty of Nursing, University of Kufa, Kufa, Iraq

### ABSTRACT

The aim of the study was to assess the psychological burden and social stigma among caregivers of children with cerebral palsy (CP) by finding out the relationship between the psychological burden of parents and their socio-demographic characteristics (age, number of family members, marital status, level of education, occupation, participation in training about CP, monthly income of the family, residency area, and house ownership).

**Material and Methods:** A descriptive design, a non-probability purposive sample of 80 parents having children with CP was conducted in the period from March to July 2023. Setting of the study: the study has been carried out on parents of children with CP at the Physiotherapy Center and Oncology Center located in Al-Saddar Medical City.

**Results:** The findings of the study revealed that the majority of caregivers were mothers. Most of the samples included their age (30–34), graduation from secondary school, and details of suffering from insufficient monthly income. Most participants had a moderate level of psychological burden and social stigma, and we found a highly significant correlation between psychosocial burden and social stigma.

**Conclusion:** The study recommended providing access to counseling and mental health services to help parents manage their psychological burden and improve their mental health. Increasing awareness and education about CP and its impact on families will reduce social stigma and improve the acceptance of children with CP. Offering support groups for caregivers to connect and share their experiences.

### ARTICLE HISTORY

Received July 12, 2023

Accepted July 31, 2023

Published July 31, 2023

### KEYWORDS

Social stigma; psychological burden; caregivers; children; cerebral palsy.

## Introduction

Cerebral palsy (CP) is a collection of symptoms brought on by abnormalities, dysfunction, or injury to the regions of the brain responsible for motor control. Sometimes other brain abnormalities show up in children with CP. CP can be caused by a brain injury that occurs during pregnancy, labor, delivery, or early life. Muscle dysfunction caused by brain damage may not worsen with time, but symptoms can alter as a kid gets older. It affects 1–2 out of every 1,000 newborns but affects 15 in 100 premature infants, which is particularly common among those with extremely low birth weight [1].

The birth of a child with a disability is the main cause of depression and anxiety for parents because there is great pressure on them because

of the child's disability and the lack of knowledge and awareness of how to care for him., so they face many challenges while caring for children with disabilities [2,3]. The World Health Organization defined the primary caregiver as "the person in a patient's environment who voluntarily assumes the role of being responsible for the patient in a broad sense; this individual is willing to make decisions by and for the patient and to cover the basic needs, either directly or indirectly" [4].

Children with CP depend heavily on their caregivers; the majority of care is provided by their mothers. Taking care of the family, providing for the household, and helping the child with CP can be heavy for moms in poor and middle-income settings. This puts a substantial burden and stress on

**Contact** Noora Farhan Hassan al-Abedi ✉ nora.farhan@uokufa.edu.iq ✉ Faculty of Nursing, University of Kufa, Kufa, Iraq.

the parents due to the intersection between poverty, social stigma, and caregiving for a child with a disability [5].

In addition, the psychological issues are compounded by the parents' sense of isolation, helplessness, stigma, and the resulting family and societal disputes. They also experience physical stress, such as insomnia, muscle and joint discomfort, and high blood pressure. Caregiver burden is an issue that has been ignored for too long and needs to be better understood and addressed [6,7]. Caregiver burden is defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the experience of care" [8]. Caring for any child requires significant resources, but the demands on these resources are typically multiplied when caring for a disabled child, adding to the care load on parents [9].

Long-term responsibility for a disabled child, combined with a necessity to face adversities and challenges associated with handling the child, leads to negative emotions, such as anxiety, sadness, anger, hopelessness, and distress, experienced by the person, and adversely affects the functioning of the parents and the entire family. According to one study, a disabled kid's reliance on others in daily tasks significantly influences the mother's psychological discomfort, and the more reliant the child is, the more distressed the mother becomes [10].

Fear and misunderstanding are the primary causes of stigma, exacerbated by inaccurate or misleading portrayals of illness. Despite widespread acceptance of the medical or hereditary nature of health disorders and the necessity for treatment, however, many individuals have negative attitudes toward those illnesses [11]. The feeling of stigma does not only fall on the affected individual; it extends to include family, friends, and people close to him. Previous research confirms that an individual associated through social context with a stigmatized individual will receive the same community treatment as the affected person [12].

Managing the psychosocial impacts of CP can be challenging because it requires long-term care. As a result, coping techniques should focus on relieving the stress of everyday care, reducing hospital readmissions, and providing appropriate psychosocial support to specific subgroups of parents to modify parental perceptions and expectations. In Iraq, mothers of children with CP face unique challenges, such as the combination of gender norms, poverty, stigmatization, a lack of support, and non-inclusive public policy. They must be addressed to improve

the quality of life for children and their caregivers [13].

Objectives of the study are (1) assessing the psychological burden and social stigma among caregivers of children with CP and (2) finding out the relationship between the psychological burden of caregivers and their socio-demographic characteristics (age, number of family members, marital status, level of education, occupation, participation in training about CP, monthly income of family, residency area, and the house ownership).

## Materials and Methods

A descriptive design was carried out throughout the present study to identify psychological burden and social stigma among caregivers of children with CP during the period from October 2022 to April 2023.

The study was carried out on parents of children with CP at the Physiotherapy Center and Oncology Center located in Al-Saddar Medical City.

A non-probability purposive sample of 80 parents having children with CP was analyzed.

### Statistical analysis

The statistical package for social sciences version 25 was used to analyze data from the study sample. The analysis included two types of statistics: 1. Descriptive statistics presented as means, frequencies, and percentages. 2. Inferential statistics: chi-square test. Bivariate Pearson's correlation test was used to ascertain the correlations. The correlation coefficient ( $r$ ) is a measure of correlation strength and direction; its value ranged from zero (complete lack of correlation) to one (ideal correlation); the higher  $r$  value close to 1 indicated a more potent correlation; the positive (no sign)  $r$  value indicated a direct (positive) correlation; and the negative signed  $r$  indicated an inverse correlation.

## Results and Discussion

Table 1 shows that the majority of the study sample are mothers as caregivers 61.2%. Concerning the dominant age of caregivers, 40% are between 30 and 34 years old, the number of family members is 3 or less 51.3%, and 25% graduated from secondary school. About 35% of the mothers were housewives, while the fathers were free workers, about 27.5%; 68.8% of them never participated in training sessions. Concerning monthly income, about 41.3% of those with sufficient monthly income live in urban areas, and 83.8% have freehold house.

**Table 1.** Statistical distribution of study sample by their demographic data. <AQ>

| Items                             | Sub-groups        | Study group (Total = 80) |              |
|-----------------------------------|-------------------|--------------------------|--------------|
|                                   |                   | Freq.                    | Percentage % |
| Caregivers                        | Father            | 31                       | 38.8         |
|                                   | Mother            | 49                       | 61.2         |
|                                   | 20–24             | 31                       | 38.8         |
|                                   | 25–29             | 9                        | 11.3         |
| Age/years                         | 30–34             | 32                       | 40.0         |
|                                   | 35–39             | 6                        | 7.5          |
|                                   | More than 39      | 2                        | 2.5          |
| Numbers of family members         | ≤ 3               | 41                       | 51.3         |
|                                   | 4–6               | 31                       | 38.8         |
|                                   | 7+                | 8                        | 10.0         |
| Level of education                | Literate          | 12                       | 15.0         |
|                                   | Primary school    | 16                       | 20.0         |
|                                   | Secondary school  | 20                       | 25.0         |
|                                   | Institute         | 13                       | 16.3         |
|                                   | College or high   | 19                       | 23.8         |
| Participated in training sessions | Not once          | 55                       | 68.8         |
|                                   | Once              | 15                       | 18.8         |
|                                   | Two times         | 7                        | 8.8          |
| Parents' occupation               | Three and more    | 3                        | 3.8          |
|                                   | Employed          | 30                       | 37.5         |
|                                   | Free work         | 22                       | 27.5         |
| Monthly income                    | Housewife         | 28                       | 35           |
|                                   | Sufficient        | 25                       | 31.3         |
|                                   | Barely sufficient | 33                       | 41.3         |
| Residency area                    | Insufficient      | 22                       | 27.5         |
|                                   | Urban             | 67                       | 83.8         |
| House ownership                   | Rural             | 13                       | 16.3         |
|                                   | Freehold          | 67                       | 83.8         |
|                                   | Rental            | 13                       | 16.3         |

Cut-off point ( $\geq 2.34$ : good;  $\geq 1.67$ : moderate;  $\geq 1$ : poor).

Table 2 shows that the majority of the study participants have a moderate level of psychological burden (57.5%).

Table 3 shows that most parents have a moderate level of social stigma (48.8%) at mean score of 2.34.

Table 4 shows that highly statistically significant correlation between psychosocial burden and social stigma.

Table 5 shows a significant relationship between parents' age and monthly income with caregivers'

**Table 2.** Overall assessment of the psychological burden scale for the study subjects.

| Items                | Freq.           | Percent | MS   | Assessment |          |
|----------------------|-----------------|---------|------|------------|----------|
| No burden            | 13              | 16.3    |      |            |          |
| Psychological burden | Moderate burden | 46      | 57.5 | 2.10       | Moderate |
|                      | Severe burden   | 21      | 26.3 |            |          |

Cut-off point ( $\geq 2.34$ : good;  $\geq 1.67$ : moderate;  $\geq 1$ : poor).

**Table 3.** Overall assessment of the social stigma scale for the study subjects.

| Items         | Frequency | Percent | Mean of score | Assessment |          |
|---------------|-----------|---------|---------------|------------|----------|
| Social stigma | Low       | 7       | 8.8           |            |          |
|               | Moderate  | 39      | 48.8          | 2.34       | Moderate |
|               | High      | 34      | 42.5          |            |          |

Cut-off point ( $\geq 2.34$ : good;  $\geq 1.67$ : moderate;  $\geq 1$ : poor).

**Table 4.** Relationship between the parents' social stigma and psychosocial burden.

| Main studied domains | Social stigma       | Psychosocial burden |         |
|----------------------|---------------------|---------------------|---------|
| Social stigma        | Pearson correlation | 1                   | 0.500** |
|                      | Sig. (2-tailed)     |                     | 0.000   |
|                      | N                   | 80                  | 80      |
| Psychosocial Burden  | Pearson correlation | 0.500**             | 1       |
|                      | Sig. (2-tailed)     | 0.000               |         |
|                      | N                   | 80                  | 80      |

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

**Table 5.** Relationship between the caregiver's psychosocial burden and their socio-demographic data.

| No. | Items                            | Chi-square | DF | p-value    |
|-----|----------------------------------|------------|----|------------|
|     | Level of education               | 8.744      | 8  | 0.364 (NS) |
|     | Monthly income                   | 11.089     | 4  | 0.026 (S)  |
|     | Residency area                   | 0.541      | 2  | 0.763 (NS) |
|     | House ownership                  | 3.113      | 2  | 0.211 (NS) |
|     | Participated in training program | 3.293      | 6  | 0.771 (NS) |
|     | Occupation                       | 7.066      | 4  | 0.132 (NS) |
|     | Age                              | 15.016     | 8  | 0.05 (S)   |
|     | Family number                    | 2.577      | 4  | 0.631 (NS) |

Cut-off point ( $\geq 2.34$ : good;  $\geq 1.67$ : moderate;  $\geq 1$ : poor).

psychosocial burden, while for the other parameters, there is no significant relationship.

Degree of freedom (df), Probability value (*p*-value), Significant (S), Non-significant (NS).

Table 6 shows a significant relationship between parents' age and caregiver type with social stigma, while for other parameters, there is no significant relationship.

Table 1 shows that more than half of the study sample (61.2%) were mothers, and these results showed that the responsibility of caring for children with CP falls largely on mothers than fathers. This finding is consistent with a study by [14] who mentioned that (88.7%) of their respondents were women. Another study conducted by [15] revealed that 97% of the caregivers of children with CP were their mothers.

Regarding the age of the participants, the study indicated that the age group (30–34) years is the dominant age group in the study with a percentage of 40.0%, and they have children 3 or less with a rate of 51.3%. Concerning the parents' education, the study indicates that 25% of them graduated from secondary school, and most of them (41.3%) had insufficient monthly incomes. These findings are consistent with [16] and report that more than half (53.3%) of the parents completed secondary school. In addition, a previous study done by [17] reported that people with higher educational attainment are more aware that advocating inclusion is desirable and are therefore more likely to endorse such views.

Concerning participation in training courses, the current results showed that caregivers who did not receive training courses represented the largest percentage of the study sample (68.8%). Regarding participants' occupations, the result revealed that most mothers were housewives, while most fathers were free workers. From the point of view of our culture, fathers spend most of their time at work and

have provider responsibility, and mothers have the responsibility for household and childcare. Hence, mothers spend all their time with their children.

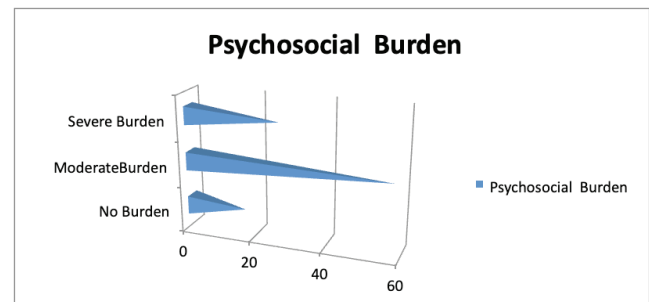
Regarding the housing area, the results of the current study revealed that about 83.8% of the study sample are urban residents, and they have a freehold. In a previous study done by Vadivelan et al. [5], they reported that several characteristics of the community influence the caregiver's stress. Community structures are very different. Therefore, in urban areas, societies are individualistic, with very little day-to-day interaction in neighborhoods. Communities are more open in rural areas, and day-to-day interactions are more frequent. Based on this, the extent of community stress will vary.

Table 2 and Figure 1 show an overall assessment of the psychological burden scale, which shows that the majority of parents have a moderate level of psychological burden (57.5%), while 16.3% of them do not have a psychological burden, whereas the percentage of those who have a severe psychological burden is 26.3%. This result is supported by Mudale et al. [18] who found that caregivers of children with CP suffer from a huge psychological burden, with 94% of them feeling frustration.

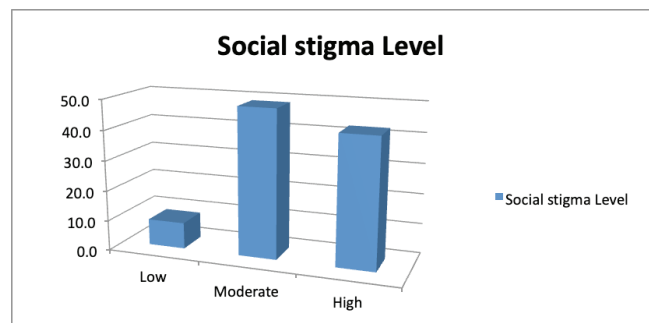
Table 3 and Figure 2 show the overall assessment of the social stigma scale, in which the majority of

**Table 6.** Relationship between the caregivers' social stigma and their socio-demographic data.

| No. | Items                                | Chi-square | DF | <i>p</i> -value |
|-----|--------------------------------------|------------|----|-----------------|
| 1   | Who are caregivers                   | 128.153    | 68 | 0.000 (S)       |
| 2   | Level of education                   | 66.484     | 68 | 0.529 (NS)      |
| 3   | Monthly income                       | 28.745     | 34 | 0.723 (NS)      |
| 4   | Residency area                       | 13.828     | 17 | 0.679 (NS)      |
| 5   | House ownership                      | 19.788     | 17 | 0.285 (NS)      |
| 6   | Participated in the training program | 47.675     | 51 | 0.606 (NS)      |
| 7   | Occupation                           | 24.464     | 34 | 0.886 (NS)      |
| 8   | Age                                  | 84.528     | 68 | 0.05 (S)        |
| 9   | Family number                        | 28.968     | 34 | 0.713 (NS)      |



**Figure 1.** Overall assessment of psychosocial burden scale for the study subjects.



**Figure 2.** Overall assessment of social stigma scale for the study subjects.

caregivers have a moderate level of social stigma (48.8%), while those with a low level of social stigma reach 8.8%, and in contrast, the percentage of those with a high social stigma is 42.5%.

Table 4 reveals a significant relationship between the parents' social stigma and psychosocial burden; if there is a social stigma, it will be accompanied by a psychological burden. A study by Vadivelan et al. [5] mentions that the mothers had no support from community members and felt isolated from others. The mothers also reported discrimination and a lack of participation in social events. Environmental stressors, such as lack of inclusive public spaces, lack of options for public transport, and unfriendly work timings and environments, were major sources of burden.

Table 5 shows a significant relationship between psychological burden and socio-demographic data such as monthly income and caregiver age. This result supported by Mohammed and Issa [19] mentions a significant association between monthly income at  $p < 0.007$  with the psychological burden. parents' age may also be significant because at this age (30–34 years), vulnerability to psychological and social burdens is high. In addition, lack of monthly income can increase the burden on the family.

Table 6 shows that there is a statistically significant relationship between who is the caregiver (father and mother) and the parents' age with social stigma. They are highly interrelated, as who the caregiver is and their age clearly influence social stigma, particularly the mother. The goal of the caregiver is to take care of the health and bear the health, psychological, and financial burdens of the individuals and their children. In this way, the caregiver will know how to deal with and meet the needs of children with CP and how to reduce the psychological and physical stress resulting from providing care [20].

## Conclusion

According to the study findings and discussion, the study concluded the following:

1. Most of the participants in the current study were mothers.
2. Most parents did not participate in the training program.
3. Most parents have a moderate level of psychological burden and social stigma.
4. Age was statistically significant, while other parameters were not significant.

5. There is a relationship between caregivers' psychological burden and social stigma.

## Recommendations

1. Providing access to counseling and mental health services to help parents manage their psychological burden and improve their mental health.
2. Increasing awareness and education about CP and its impact on families to reduce social stigma and improve the acceptance of children with CP.
3. Offering support groups for caregivers to connect and share their experiences, which can reduce social isolation and provide a sense of community.
4. Encouraging healthcare professionals to provide more support and resources to families of children with CP to alleviate some burdens on them, such as respite care and home health services.

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