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A Study To Understand The Issues In Physical Health And Coping Strategies Of Parents With Disabled Child

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ABSTRACT

Objective: The purpose of this study was to better understand the physical health problems faced by parents with disabled child and kind of coping strategies that the parents use to tackle their physical health problems

Material and Methods: This is an observational study conducted on 30 parents having children with neurological or neurodevelopmental disorders; Nordic musculoskeletal questionnaire and World Health Organization Quality of Life (WHOQOL-BREF) were administered to measure physical health and their Quality of life respectively. Parents were asked to attend one scheduled face-to-face interview designed to gather information regarding their coping strategies that are used to tackle their physical health problems.

Results: According to Nordic musculoskeletal questionnaire, Low back pain and shoulder pain was the most common pain (76.66%). On WHOQOL-BREF, Social relationship domain was observed to be the best while the physical domain had the lowest score. The main coping strategy used by the parents is taking a break [73.33%] followed by undertaking medications like pain killers [43.33%], whereas the least are exercises and massage [23.33%].

Conclusion: Among parents with disabled child, Low back pain and shoulder pain were the most common reported physical health problems and the main coping strategies were taking breaks and medications.

Keywords: *caregivers, coping strategies, Physical health, special child*

1. INTRODUCTION

Developmental disability refers to any physical or mental impairment that could hinder or restrict a child's capacity to develop emotionally, physically, or cognitively[1]**.** Cerebral palsy, down syndrome, intellectual disability, autism spectrum disorder, ADHD, learning disability, epilepsy, etc. are all considered to be among the various conditions that fall under the category of developmental disability. Parenting a child with developmental disabilities is a difficult journey since they must fulfil more demands than parents of children without disabilities[2].

QOL is a multidimensional concept that includes the subjective perception of an individual's life in terms of one's psychological state, physical health, social support, beliefs, and relationship with the quality of one’s environment[3]. Shalock further advocated the importance and utilization of QOL as a framework for service delivery and quality improvement in research in developmental disabilities[4]. Disability in children may have an impact on the quality of life (QOL) of their parents[5].

The WHO defines ‘Health in the sense of the overall well-being of a person, physically, mentally, and socially’. Physical health is not just the absence of sickness and disease; it is the complete well-being of the body. It is important because it is intricately linked to other aspects of well-being. Parenting a disabled child may have a negative impact on parents' physical health[6–11]. Furthermore, most studies have focused on caregivers’ psychological health, although physical health effects may also exist among caregivers [8]. When the level of functional dependence increases in disabled children, there occurs an excessive physical burden on mothers; this physical burden further increases in lifting, carrying and transfer activities in particular condition.

Coping strategies are "The cognitive and behavioral efforts required to manage specific external and/or internal demands that are assessed as taxing or exceeding the person's resources"[12]. Qualitative studies and small-scale survey evidence suggest that mothering a child with a disability can be stressful and exhausting and that mothers experience more stress than fathers because they perceive their roles differently and cope differently[13,14]. Indeed, the types of coping strategies used by parents of children with disability were found to have more decisive effect on their level of stress than the stressors itself[15]. Among the few studies that have investigated the interactions between the concepts of stress, coping strategies and QoL among parents of children with disability[16,17].

Numerous studies have focused mainly on the level of stress (mental health) experienced by families with impaired children, how they cope, what supports them, and what coping mechanisms they employ but not regarding physical health[18]. To ascertain the long-term physical health effects of parenting a child with a particular health care need, more longitudinal, population-based studies are required. The needs of the carers are rarely taken into consideration when treating and rehabilitating disabled children. Even carers may require intervention to manage the physical, mental, and emotional burden they experience while providing care for a loved one. The purpose of this study was to better understand the physical health of parents with disabled children and their coping strategies. The findings of this study could aid rehabilitation professionals in understanding the coping strategies used by parents to tackle their physical health problems.

AIM:

1. To find out the major physical health problems faced by parents with disabled child
2. To determine different kind of coping strategies that the parents use to tackle their physical health problems.

2. MATERIAL AND METHODS

This study was approved by the Ethics committee for student's project - Sri Ramachandra institute of higher education and research (reference - **CSP/23/APR/127/364**). This study was also registered in Clinical Trail registry - India with registration number **CTRI/2023/06/054414.**This observational study was conducted in the Vidhya Sudha Sri Ramachandra learning center for children with special needs. A sample of 30 parents having children with neurological or neurodevelopmental disorders were included in the study. Parents who have not lived with a physically disabled child for more than two years and who were being treated for severe mental illnesses at the time of the interview were excluded. Eligible parents were informed about the study objectives and assured of their confidentiality regarding the information provided. All participants provided their informed consents.

Nordic Musculoskeletal Questionnaire: The Nordic Musculoskeletal Questionnaire (NMQ) is a valid, reliable, and sensitive screening tool that is frequently used in epidemiological studies carried out in many countries to examine the prevalence of musculoskeletal symptoms in various body areas in an occupational health setting, including the teaching profession. It can identify symptoms in the neck, back, shoulders, and extremities.

Parents were asked to attend one scheduled face to face interview designed to gather information regarding their coping strategies that are used to tackle their physical health problems. A single researcher performed data collection through an individual face to face in depth semi – structured interview at the hospital site. A pilot study with 2 individuals were conducted to assess whether the questions is understandable and / or adjustments are needed. The interviews were digitally recorded and then completely transcribed. Interview lasted on average 15 min.

WHOQOL-BREF Questionnaire: WHOQOL-BREF Questionnaire is a self-administered instrument developed by WHO. Four domains of QOL are measured: Physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items) are the four QOL domains that are assessed. 26 items comprise the scale, which has a total score range of 26–130. The mean score for each domain is then determined. This mean domain score is then converted into a scaled score, with a higher score indicating a higher QOL, by multiplying the domain score by 4. This scale showed strong content validity, test-retest reliability, internal consistency, and discriminant validity.

Data analysis

Data was analyzed using SPSS 2022 version software

3. RESULTS

Flow of participants, therapists, centers through the study

This study was done on 30 subjects and the result were analysed.

Table 1. Baseline characteristic of study participants.

VARIABLE	AGE
MEAN ± S.D.	31.83 ± 4.81

S.D. – Standard Deviation

Table 2. Domain wise distribution of WHOQOL-BREF Scores

DOMAIN	PHYSICAL DOMAIN	PSYCHOLOGICAL DOMAIN	SOCIAL RELATIONSHIP DOMAIN	ENVIRONMENTAL DOMAIN
MEAN±S.D.	36.38 ± 7.78	51.21 ± 9.39	66.17 ± 14.78	54.54 ± 10.89

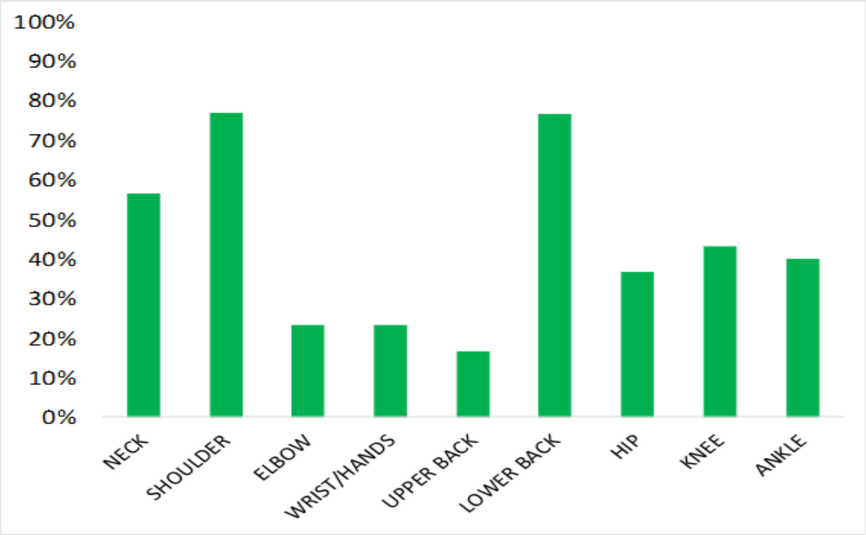
S.D.=standard deviation

Shows the mean scores and standard deviation (SD) for each domain of parents having a child with a disability on the WHOQOL – BREF scale. According to domain scores, Domain 1(physical domain) had a low score (both mean and SD), whereas Domain 3 (social relationship) had the highest score (both mean and SD), suggesting the QOL is worst in Domain 1 and best in Domain 3.

Table 3. Distribution of study subjects according to the Nordic musculoskeletal questionnaire

BODY PART	NO	YES
NECK	13(43.33%)	17(56.66%)
SHOULDER	7(23%)	23(76.66%)
ELBOW	23(76.66%)	7(23%)
WRIST/HAND	23(76.66%)	7(23%)
UPPER BACK	25(83.33%)	5(16.66%)
LOWER BACK	7(23.33%)	23(76.66%)
HIP	19(63.33%)	11(36.66%)
KNEE	17(56.66%)	13(43.33%)
ANKLE	18(60%)	12(40%)

N= Numbers



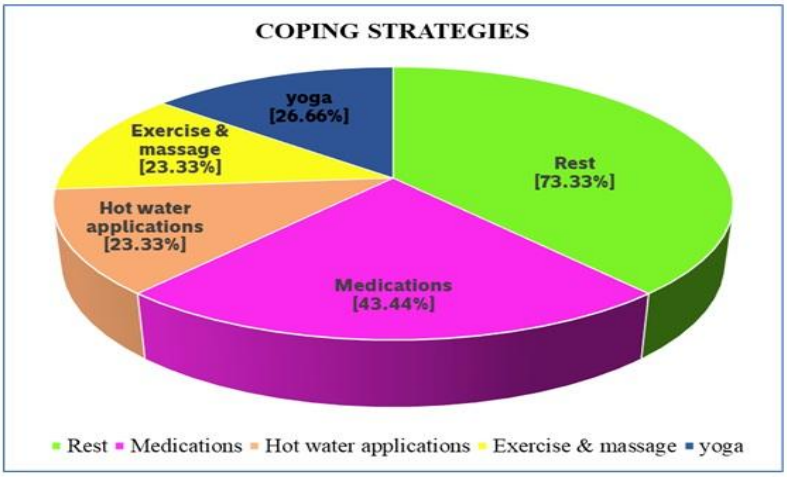
Distribution of study subjects according to the standardized Nordic questionnaire

Shows that out of 30 subjects, Low back pain and shoulder pain was the commonest sites of pain (76.66%) in which left shoulder pain is predominant than right (33.33%) followed by neck pain (56.66%) and knee pain (43.33%).

Table 4. Distribution of study subjects according to coping strategies used to tackle their physical health problems.

Coping strategies	**Rest**	**Medications**	**Hot water application**	**Exercise & massage**	**Yoga**
N (%)	22[73.33%]	13[43.33%]	7[23.33%]	7[23.33%]	8[26.66%]

N = number of people



Distribution of study subjects according to coping strategies used to tackle their physical health problems.

The main coping strategies used by parents with disabled child is taking a break [73.33%] followed by undertaking medications like pain killers [43.33%], doing yoga [26.66%], hot water application [23.33%] and least depend on doing exercises and massage [23.33%].

4. DISCUSSION

The primary purpose of this study was to identify the major physical health problems faced by the parents with disabled child. We found that the Low back pain and shoulder pain rates were higher in parents with disabled child. Leaning forward, rotation, lifting, pushing, and pulling movements by mothers during care of their disabled children and their activities of bathing, clothing, carrying, and feeding their children create an increasing stress on musculoskeletal systems of mothers[19]. Tong et al. believes that both physical factors (child transferability) and psychological aspects (carers' mood) are associated with LBP in caregivers[20]. Previous study found that low back pain incidence was higher in female caregivers of children with physical disabilities and this ratio was lower in caregivers of the children without physical disabilities[21]. It was mentioned that the low back pain could cause impairment in the quality of life in the parents with disabled children[22].

Our study also reported that overall quality of life of parents with disabled child. Some of the studies suggested that parents of disabled children have a lower quality of life than parents of typically developing children[23,24]. According to our research, the lower QoL score in the physical domain of QoL is consistent with the results of earlier studies[25–28]. Physical health, sleep, pain, and coping with daily living and physical activities are all part of the physical domain of quality of life. Previous studies have shown that the type and degree of the child's impairment has an impact on parental quality of life[29,30]. The repetitive strain experienced by some parents might lead to chronic pain[31]. Thus, parents' physical health QoL domain were affected followed by psychological domain. Some studies have demonstrated the correlation between the symptoms of depression and the impairment in physical health and chronic pain[32,33]. It is believed that if the QOL of parents is improved, better parental care will improve and further enhance the well-being of their children[31].

Secondary purpose of the study was to identify how parents with disabled child managed, what kind of coping strategies they used to tackle their physical health problems. The qualitative analysis was based on the key phrases that described the coping strategies used by the parents[34]. In this study we found that parents mainly focused on rest and medications as a coping strategy rather than doing exercises, but regular exercise is found to improve physical health and vitality, lowers depression, and improves quality of life [35].

The results of this study also indicate that professionals who work with parents of children with disabilities need to be aware of the coping strategies that the parents use to deal with the demands of parenting and their physical health. In addition, health professionals need to provide adequate formal support to parents of children with disability. This would be especially beneficial in developing countries whereas formal support is almost non-existent. Rehabilitation programs can be planned to provide physical support to the caregivers to ease the burden. Based on our findings most of the parents suffered from back pain and shoulder pain, Training on back and shoulder health must be given to this group of mothers before their pain becomes chronic. Mothers should avoid positions bringing load onto the low back during exercises with rehabilitation purposes, training for transport of the child should be given to mothers, and rendering the child as independent as possible in their daily activities must be supported.

5. LIMITATIONS AND FURTHER RECOMMENDATIONS

Limitations and further recommendations for this study must be acknowledged. First, the sample size is small. All these disabled kids attending the same special school, which was not representative of all socioeconomic groups. To validate the findings of this study, we need a large sample size. As this study is cross-sectional, we are unable to identify any causal relations. More variables could be added to improve understanding of the relationship between various variables. Second it should be noted that the information was collected by a self-administered questionnaire; this is of a verbal nature and can produce a mismatch between perceived and actual behavior.

Conclusion: This study concludes that majority of the subjects were having low back pain and shoulder pain followed by neck pain and knee pain. And the main coping strategies used by parents to tackle their physical health problems is taking a break followed by undertaking medications like pain killers but least aware on doing exercises. Future line of the study could aid rehabilitation professionals by providing the therapeutic interventions to parents along with disabled child to tackle their physical health problems.

6. DECLARATIONS

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Author contributions

Authors are required to include a statement of responsibility in the manuscript that specifies the contribution of every author. The following statements should be used:

Conceptualization, C. R. Praveenkumar. and E. Monica.; Methodology, C. R. Praveenkumar, P. Parthiban. and E. Monica.; Validation, C. R. Praveenkumar, P. Parthiban. and E. Monica Formal Analysis, C. R. Praveenkumar, P. Parthiban. and E. Monica.; Resources, C. R. Praveenkumar. and E. Monica.; Data Curation, C. R. Praveenkumar. and E. Monica.; Writing –

Original Draft Preparation, C. R. Praveenkumar, P. Parthiban. and E. Monica.; Writing – Review & Editing, C. R. Praveenkumar. and E. Monica; Visualization, C. R. Praveenkumar. and E. Monica.; Supervision, C. R. Praveenkumar and P. Parthiban.; Project Administration, C. R. Praveenkumar. and E. Monica

Conflicts of interest

Competing interests: The authors declare no competing interests

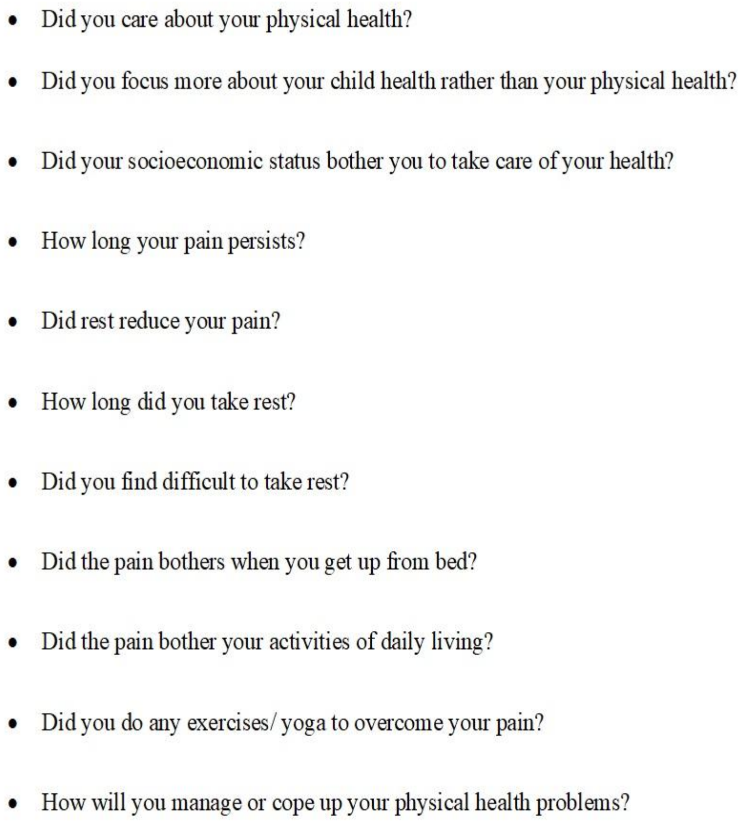
Data availability

All data generated or analyzed during this study are included in this published article

Ethics approval

This study was approved by the Ethics committee for student’s project - Sri Ramachandra institute of higher education and research (reference - **CSP/23/APR/127/364**)

Figure S3. Coping strategies (open ended questions)



- Did you care about your physical health?
- Did you focus more about your child health rather than your physical health?
- Did your socioeconomic status bother you to take care of your health?
- How long your pain persists?
- Did rest reduce your pain?
- How long did you take rest?
- Did you find difficult to take rest?
- Did the pain bothers when you get up from bed?
- Did the pain bother your activities of daily living?
- Did you do any exercises/ yoga to overcome your pain?
- How will you manage or cope up your physical health problems?

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