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LOW BACK PAIN AND ITS IMPACT ON ACTIVITIES OF DAILY LIVING AND GENERAL HEALTH IN PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

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Abstract:

This study intended to evaluate low back pain and its impact on activities of daily living in primary caregivers of children with cerebral palsy (CP). [Method]: A community based cross sectional study was conducted on 100 primary caregivers with chronic low back pain. A validated questionnaire for work analysis and Modified Oswestry low back pain disability questionnaire were used to study the impact of low back pain on Activities of Daily Living and general health in primary caregivers of children with CP. [Results]: By visual analogue scale, 47% of the subjects didn't have any low back pain at rest, while 51 % of them experienced mild pain at rest. But, 60 % of the primary caregivers experienced moderate pain on activity, followed by 28% with moderate pain.[Conclusion]:Maximum number of study subjects experienced severe low back pain on activity. Most of them successfully managed the pain with rest. As per Modified Oswestry low back pain disability Index, most of the primary caregivers fell under moderate to minimal disability category and least in severe disability category.

Key Words: Low Back Pain, Primary Caregiver, Cerebral Palsy, Activities of Daily Living & General Health

Introduction:

Cerebral Palsy is defined as a disorder of movement and posture due to a defect or lesion of the immature brain; however it is accompanied by other impairments that reduce functioning. Every type of cerebral palsy is characterised by abnormal muscle tone, reflexes, motor development and in coordination. It may subsequently lead to tightmuscles, joint and bone deformities and permanent fixed contractures. Other disabling features include seizures, learning disabilities, and communication, behavioural problems, and intellectual impairments, visual and hearing difficulties [1].Hence being a complex clinical entity these children often need special care. Children with cerebral palsy require assistance in performing daily activities and ambulation. They need endless care giving as many of them have limitations in self-care functions such as feeding, dressing, bathing, toileting and mobility. The care and treatment of children with cerebral palsy can be quite demanding in terms of time, stress and expenditure. Sigrid Ostenjo & Eva Brogren et alfound a large variability in functioning, mobility, self-care and social function levels of the affected children because of heterogeneity of cerebral palsy. [2]

The caregivers need to provide care regularly under complex circumstances thereby keeping a balance between family, their careers and other responsibilities. A study by Sawyer MG & Bittman Metal stated that on an average mothers spent 6hrs/24hrs and 8.3hrs/24hrs caring for children with cerebral palsy on weekdays and weekends respectively[3]. Studies have demonstrated huge increment in care requirement in view of increased needs of the children with cerebral palsy (in addition to the usual needs of children), and have also affected parent's physical, social wellbeing and financial stability. [4,5]. Thus while care giving is a normal part of being a parent of any young child providing high level of care required by the child with long term functional limitations can become burdensome. In this process the caregivers tend to neglect their own health problems. It exposes the caregivers to risk factors of various musculoskeletal disorders [6]. These include back pain, neck pain, shoulder pain and leg pain. But, low back pain was found to be the most prevalent pains among the caregivers of children with cerebral palsy [7]. Another study by Sharan D and Ajeesh PSet al also had similar observation. According to the study low back pain was most commonly reported musculoskeletal problem (58%), followed by knee pain and shoulder pain [6].As any other chronic pain, low back pain would also impact an individual's day to day life. Hence it is important to consider the impact of care giving resulting into low back pain and its effect on day to day life among primary caregivers who play a significant role in the cerebral palsy child's rehabilitation process which needs to be studied.

Related Work:

A study done by M.B.Byrne, DA Hurley et al on health status of caregivers of children with cerebral palsy states poorer health among female caregivers than male caregivers in both physical and mental health domains of the SF-36 [7].E Davis, A Shelly et al, in a study on, the impact of caring for a child with CP:QOL of

mothers and fathers concluded that caring for a child with CP affects a parent's physical and social wellbeing, freedom and independence, family wellbeing and financial stability [4]. Kurtulus Kaya, Sibel Unsal-Delialioglu et al conducted a study on, Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy which concluded deterioration of mental health in mothers with cerebral palsied child may be causing them to experience more LBP. Experience of increased LBP causes deterioration of health-related QOL [8].A study by Sharan, Deepak et al on, Musculoskeletal Disorders in Caregivers of Children with Cerebral Palsy Following a Multilevel Surgery quoted that patients of cerebral palsy need assistance for their self-activities which expose the caregivers to different risk factors of musculoskeletal disorders [6].Henry C. Tong, MD et al, conducted a study on, Low Back Pain in Adult Female Caregivers of Children with Physical Disabilities which concluded prevalence of LBP to be higher in caregivers of children needing assistance with transfers. This increased prevalence is associated with the transferability of the child and mood of the caregiver. Results of this study suggest that physical and psychological factors both contribute to the presence of non-occupational LBP [9].

Methodology:

This study was a community based cross sectional study. About100 caregivers having children with cerebral palsy could be included in this study through convenience sampling within the duration of six months. Study samples were recruited from multiple centres across Mumbai and Navi Mumbaiviz:-a) D Y Patil Hospital(Nerul, Navi Mumbai), b)Able Disable All People Together (ADAPT) at Bandra, Colaba & Dharavi,c)B Y L Nair Charitable Hospital (Mumbai), d) Chetana rehabilitation centre (Thane), e)National Society For Equal Opportunities For The Handicapped (NASEOH, Chembur), f)Child Rehabilitation Centre (Nerul).Primary caregivers of children(0-18 years – pediatric age group as recommended by IAP) with cerebral palsy, having chronic low back pain were included in the study. Caregivers having a history of back surgery, recent fracture and any kind of congenital condition were excluded from the study.

Procedure: Ethical Approval: The study was approved by the Institutional Ethics & Research Committee at D Y Patil University. Written informed consent was obtained from all the subjects. Subjects were assured that the information regarding their identification obtained during the study would be strictly kept confidential.

A validated questionnaire including demographic data, details of the child, and characteristics of the low back pain experienced by the caregivers was used. Modified Oswestry Low Back Pain Disability Questionnaire (ODI Version 2.1a) was used to identify level of disability associated with low back pain and its effect on everyday life. The Questionnaire was administered to 100 primary caregivers with chronic low back pain and children with cerebral palsy by face to face administration of the questionnaire at the respective centres. Modified ODI scores were calculated for all subjects. The information obtained from both the questionnaires was analysed using percentages and graphs. Microsoft word and Excel were used to generate graphs, tables etc.

Results:

In the present study, out of 117 caregivers approached, 100 (subjects of present study) primary caregivers reported to have low back pain. i.e 85% of the caregivers had low back pain.

Demographic Variables		**Percent (%) Subjects**
Age of caregivers	20-40 years	74%
	41-60 years	25%
	61-80 years	1%
Gender of caregiver	Male	10%
	Female	90%
Educational status	Not Educated	4%
	Primary school	2%
	SSC	42%
	HSC and above	52%
Occupation	Housewife	76%
	Employed	24%
Relationship with the child	Mother	90%
	Father	10%
	Grandparents	1%
Availability of help	Yes	38%

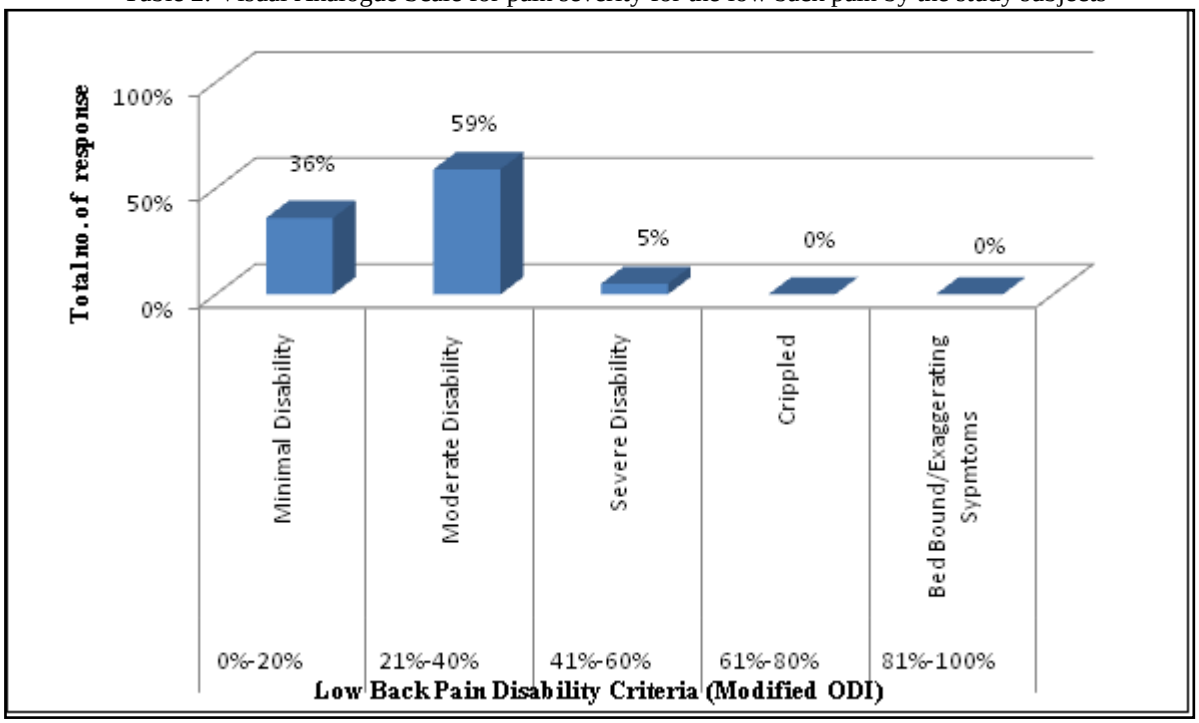
Table 1: Demographic information of female caregivers (study subjects, n=100) and children with cerebral palsy

Out of 100 samples, according to the Visual Analogue Scale, 60 % of the primary caregivers experienced moderate pain on activity while only 2% samples had moderate pain at rest indicating increase in pain for the study subjects. Similarly, about 47% of the subjects didn't have any low back pain at rest, while 51

% of them experienced mild pain. None reported severe pain at rest, whereas 12 % subjects complained of severe pain on activity. Majority of the subjects (60%) had moderate intensity of pain

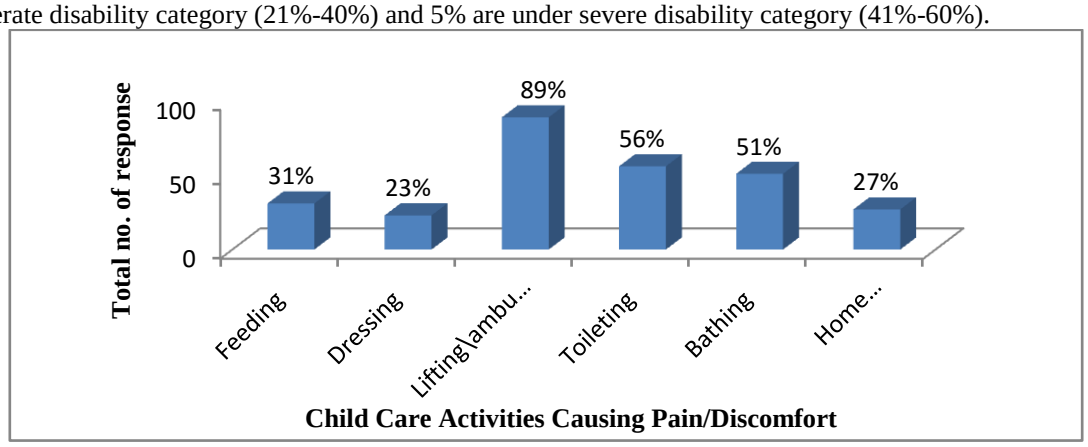
Pain Intensity Ranges	Frequency on Rest	Frequency on Activity
No pain (0-0.4 cm)	47%	0%
Mild pain (0.5-4.4cm)	51%	28%
Moderate pain (4.5-7.4cm)	2%	60%
Severe pain (7.5-10cm)	0%	12%

Table 2: Visual Analogue Scale for pain severity for the low back pain by the study subjects



Graph 1: Percent disability as per Modified Oswestry low back pain disability Index

36% of primary caregivers were found to be under minimal disability category (0%-20%), 59% were under moderate disability category (21%-40%) and 5% are under severe disability category (41%-60%).



Graph 2: Activity of child care associated with maximum discomfort among caregivers

The study found that 89% of the primary caregivers experienced maximum discomfort during lifting their child

The study found that 89% of the primary caregivers experienced maximum discomfort during lifting their child or while helping them to ambulating , 56% had discomfort while aiding toileting activities of their child, 51% while bathing the child, 31% while feeding the child, 27% during their child's exercise time and for 23% caregivers complained of discomfort while dressing their child.

Discussion:

This study intended to evaluate low back pain and its effect on everyday life in primary caregivers of children with cerebral palsy using a validated questionnaire and ODI Version 2.1 a. During the sampling procedure, out of 117 caregivers approached, 100 (subjects of present study) primary caregivers reported having low back pain. This signifies that 85% of the caregivers had low back pain. According to a comparative study done to compare musculoskeletal pain among mothers of children with cerebral palsy and mothers of healthy

children by Kurtulus Kaya & colleagues, it was found that low back pain was significantly higher among mothers having children with cerebral palsy. It also resulted in deterioration of health-related QOL of these women [8]. Of the 100 study subjects, 90% were females and 10% males. A study by Singogo C, and Mweshi M et al discussed that parenthood of a child with disability is a proven risk factor for back problems in cases of both males and females [10].Another study by Prior M and Grimmer KAet al also states that caring for a child with disability affects both parents. But, the author states that the daily lives of mothers are often affected more as in most cases they are the primary caregivers [11]. The fact can't be denied that it's mostly mothers who provide primary care to the disabled children, probably due to social and cultural structures. Dependency of children on their mothers for activities of daily living has seen to be correlating with the severity of their mother's back pain [12].

The mean age of the subjects was found to be between 35 +8.87years. About 96% were educated while 4% were uneducated. 76% of the caregivers were housewives. Sanders MJ & Morse T in their study documented an association between employment status and number of hours of housework [13]. It was noted that full time housewives spent significantly longer hours doing housework and hence is also linked with musculoskeletal pain among housewives. The housework related stress and fatigue, repetitive movements and awkward positions during housework chores were all significantly associated with increased low back pain severity [14]. Some (38%) of the primary caregivers had availability of extra help for child care or some part of household chores comprising cleaning, washing clothes and utensils, while most(62%) of them did not receive any extra help. They had to tackle all these responsibilities independently, along with caring for the cerebral palsy child. Lack of extra availability of help in child care and household chores may reflect on exacerbation of symptoms affecting low back pain thus resulting into disability in performing activities of daily living. According to a study by Sara Green it was found that assistance of grandparents in routine care of children with disabilities had a positive impact on the parental well-being [15]. Apart from grandparents, in an era of nuclear family affordability for extra help is questionable. But commenting on this aspect requires detailed evaluation of socioeconomic status which wasn't a part of this study. Around60% of the study samples bore more than one child, ranging from 2-5 children including one child with CP.Hence it can be commented that an increased impact on the back pain can be expected among primary caregivers, who need to take special care of CP child along with their other siblings.

Scores achieved on Modified Oswestry Disability Questionnaire can be classified as 0% to 20% as mild disability, 21% to 40% as moderate disability, 41% to 60% as severe disability, 61% to 80% as crippled and 81% to 100% as bed bound [16]. According to this classification, about 36% of the study subject's score fell under minimal disability category. Although this group could cope with most of the activities of daily living, they faced difficulties in lifting heavy weights off the floor, standing for prolonged periods, and homemaking activities. Scores of around 59% of the study subjects could be classified under moderate disability category. This group experienced more pain, and it prevented sitting and standing for more than an hour and lifting heavy weights off the floor, but could manage if the weights were conveniently positioned. Further pain prevented this group from participating in more energetic social activities (e.g.: sports, dancing). Though pain caused difficulty in travelling, this group could manage most of the homemaking and job related activities. But, pain prevented them from performing more physically stressful activities like lifting, vacuuming etc. 5% primary caregivers could be categorised under severe disability category. Pain remained the main problem in this group, with affection of activity of daily living in most of the domains. These primary caregivers had little to no effect of pain medications on the low back pain. They reported to be slow and careful in most aspects of personal care and required help and could lift only very light weights. They avoided lifting heavy weights, walking, sitting and standing and required frequent change in postures to relieve pain. Social life and travelling domains showed higher disability scores and desired a need of help in homemaking chores. But out of 5 subjects in this category only 3 had availability of extra help for carrying the child and their caring activities.

According to VAS, 98% of the primary caregivers experienced mild to no low back pain at rest. About 60% experienced moderate intensity of pain, 28% experienced mild intensity and 12% experienced severe intensity of low back pain on activity. The study included caregivers with chronic low back pain, i.e. pain present since3months or $\geq$ 12 weeks. A chronic LBP may originate from an injury or stresses on different structures of the body including bones, muscles, ligaments and facet joints [17]. Though 47% of the study subjects didn't report any pain at rest and 51 % had only mild pain, everyone reported increase in intensity with activity. The aggravating factors for most of the study subjects included forward bending (63%), squatting (28%), sitting without support (60%), standing for prolonged periods (66%), rotating, lifting and the techniques used during lifting and carrying the child (90%).Similar findings were noted in a study by Cassisi JE and Sypert GW et al on patients having chronic LBP. It was noted that physical activities, particularly bending, extending, twisting and lifting aggravated LBP symptoms, whereas restriction of pain-producing activities resulted in improvement, at least temporarily in these patients [18].In the present study too about 96% managed their low back pain by taking rest, and reported it to relieve their pain completely, indicating mechanical nature of the low back pain.

Among child care activities, 89% of the caregivers mentioned lifting and ambulating activities to be producing discomfort followed by activity of assisting child's toileting activities and assistance in bathing activities of the child. About 31% had discomfort while feeding the child as they would take 30-60 minutes to be fed completely. It can be noted that the activities affected in childcare require simulation of activities reported discomforting in Modified Oswestry low back pain disability Index by the subjects.

Conclusion:

Most of the caregivers didn't have any low back pain or just had mild pain at rest. While on activity, maximum study subjects experienced severe low back pain on activity. As per Modified Oswestry low back pain disability Index, most of the primary caregivers fell under moderate to minimal disability category and least in severe disability category. Among child care activities, the caregivers experienced maximum discomfort in lifting and ambulating with the child.

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