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Original Research Article

A Qualitative Study on Parents and Caregiver of Children with Cerebral Palsy's Opinions about the Value of and Compliance with Exercise Regimen

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ABSTRACT

Background: Cerebral palsy (CP) is a prevalent childhood disability caused by developmental issues in the brain, leading to posture movement and impairments. Caregivers of children with CP often experience heightened stress due to factors such as the caregiver's attributes, the extent of the child's disability, their shared history, and social elements. Despite the familycentered approach in research. comprehensive perspective on the overall impact on parents and factors influencing their coping mechanisms is lacking. Our study aims to fill this gap by exploring caregivers' perceptions of the value of and compliance with prescribed regimens for children with CP, contributing to the development of more effective, holistic, and family-centered interventions for managing CP. Aim of the study: Explore perceptions about the value of exercise regimens for children with cerebral palsy. Objective: To evaluate the importance of exercises in terms of physical, general health and psychological well-being in children with cerebral palsy (CP).

Material and Method: A total of 100 participants, male and female from different areas and town of Surat city were selected

for the study as per the eligibility criteria. Age range of the child was 1-15 years. An interview-based questionnaire was developed to assess the awareness and validated for its content validity by five experts. After validation, participants were asked to fill out the questionnaire and the data was transferred to Microsoft excel and IBM SPSS for further analysis.

Result: Among the study participants, 85% of respondents emphasize importance of exercises. 57% reported significant improvements in mobility. While more significant improvements are noted in muscle strength (60%) and coordination and balance (62%). The impact of exercises on overall health is considered significant by 72% and on independency was 57%. Furthermore, 67% highlight the significant role of exercises in encouraging emotional wellbeing and confidence building.

Conclusion: Individuals were found to have a good understanding of the importance of exercise to improve overall health, balance coordination, muscle strength, confidence, social interaction in Surat city. It is more significant with education of the parents and caregiver of child with cerebral palsy. This study showed that opinion about the value of and compliance with exercise regimen was equivalent to that of developed countries

Keyword: Cerebral Palsy (CP), Parenting caregivers, Exercise regimen, Physiotherapy, Pediatric rehabilitation, Perspectives, Caregiver burden, Therapy adherence.

INTRODUCTION

Cerebral palsy is a condition that affects movement and posture. It's caused by issues in the brain that occur when a baby is still developing in the womb or as an infant. This condition doesn't get worse over time. People with cerebral palsy might also have problems with feeling different sensations, understanding things, communicating, and behavior. They might also have epilepsy and issues with their muscles and bones.¹ Presently, the family-centered approach in research on planning and implementing interventions primarily concentrates on various facets of parental well-being, exploring potential factors influencing their quality of life through diverse samples and methodologies. This diversity in research approaches has led to the absence of a comprehensive perspective, hindering a more accurate comprehension of the overall impact on parents and the identification of factors influencing their coping mechanisms positively or negatively.²

In contemporary practices, the preferred approach involves collaborative decisionmaking between parents and therapists when determining goals and implementing interventions. This shift towards shared goal setting and decision-making, as highlighted by Bamm and Rosenbaum in 2008, is physical evident not only in occupational therapy but also in overall pediatric care for children with disabilities or special health care needs, reflecting a transition from patient-focused to familycentered care, as observed by Arango in 2011.² The educational system plays a crucial role in empowering individuals to reach their fullest potential and integrate effectively into society.³ It has been

suggested that individuals with cerebral palsy should uphold elevated levels of physical fitness compared to the general population. This is deemed necessary not only to counteract the decline in function associated with the natural aging process, such as decreased strength and endurance but also to address changes related to their condition, such as spasticity, contractures, pain, and reduced mobility. The combined impact of these changes heightens the risk of an accelerated functional decline, which may be further exacerbated by a progressive loss of fitness.⁴

Upon the birth of a child with a disability, parents are confronted with the diagnosis and must adapt their caregiving and expectations accordingly. Families of such children encounter distinctive stressors and challenges over time (Lin 2000). In contemporary pediatric physical therapy for children with chronic physical disabilities, there is a growing emphasis on involving parents more actively. Historically, physical therapy primarily focused on addressing impairments and their perceived impact on a child's daily functioning, a realm dominated by therapists and physicians, with minimal parental engagement. Only in recent times have physical therapists recognized the potential role of parents. Subsequently, ongoing debates have shaped the prevailing view that parents should play an active role, collaborating as equal partners therapists in determining the goals and content of their children's physical therapy.⁵ Children with cerebral palsy require longterm therapy that is centered on meeting their specific requirements since they struggle in many areas of functioning. This to study's goal was examine professionals who interact with kids and teenagers who have cerebral palsy exhibit family-centered behavior.⁶ Understanding the impact of exercise training, specifically a combination of strength and endurance exercises, on muscle functions relevant to daily activities is crucial for individuals with cerebral palsy (CP). However, there is a lack of studies examining the effects of a

functionally integrated strength and endurance exercise regimen on functional performance in CP participants.⁷ all children with cerebral palsy should participate, to the degree that they are able, in aerobic, muscle strengthening anaerobic, and activities based on the current body of data.8 In North America, a family-centered strategy has been progressively embraced by clinics, hospitals, and community-based support groups throughout the last ten to fifteen years. Numerous medical experts, including pediatric neurologists, children in these settings who have cerebral palsy (CP) or other neurodevelopmental problems. These kids frequently have complicated, ongoing needs, which are best served by a family-centered approach to service delivery. Using the International Classification of Functioning, Disability and Health framework, data analysis revealed differences between Indian and Canadian parents in addressing challenges related to their children's cerebral palsy. In this context, it is crucial to promote education, counseling, and awareness about cerebral palsy, which can positively impact parents, society, and healthcare professionals in both Canada and India. Cerebral palsy (CP) refers to a set of enduring conditions affecting movement and posture, leading to limitations in activity. Motor disorders CP associated with are frequently accompanied by challenges in sensation, perception, cognition, communication, and behavior. Additionally, individuals with CP may experience epilepsy and secondary musculoskeletal issues. Understanding these complexities of cerebral palsy is essential for developing effective strategies and interventions to improve the quality of life for these individuals. 10 The prevalence of cerebral palsy (CP) is documented to range from 1.5 to 3 cases per 1000 children. 11 The degree of parental stress has been observed to correlate with both the severity of children's diagnoses and disabilities, as well as the presence of concurrent behavioral issues.¹² The caregivers of children facing developmental disabilities undergo increased stress, compromised mental well-being, feelings of devaluation and self-reproach, as well as diminished physical functionality and fatigue. As a result, the main caregiver, typically the mother, may encounter various psychosocial challenges.

Moreover, mothers of children experiencing severe mental disorders and intellectual disabilities exhibited elevated occurrences of physical health issues alongside a negative assessment of their overall wellbeing.¹⁵ Stress can arise when there is a disruption in the equilibrium between external environmental pressures and the perceived internal capacity especially when these demands hinder the pursuit of other life goals. 16 The objective of physiotherapy is enhance to independence of the affected child. The ultimate aim is the restoration of adaptive functions and the improvement of postural control, locomotion, and manipulation.¹⁷ The World Health Organization (WHO) identifies limb movement function as the central rehabilitation objective, emphasizing the significance of earnestly addressing walking capacity training in children with palsy (CP). The cerebral intervention involves addressing motor through approaches issues such orthoses, physiotherapy, and medical treatment.¹⁸ The arrival of a child with developmental disabilities is a stressor for the family, particularly impacting mothers who often experience feelings of guilt and a heightened sense of responsibility, attributed their personal more to characteristics compared to other family members. Consequently, mothers frequently engage in compensation strategies to cope and address their children's with disabilities.19

Effective collaboration between families and professionals enhances the functional outcomes of rehabilitation, elevates the quality of daily programming across the entire continuum of care, and contributes to overall patient and family satisfaction.²⁰ Participation is broadly defined as

involvement in various aspects of life, encompassing physical, social, and personal engagement in activities. This involvement is crucial for individuals with disabilities.²¹ A fundamental objective of rehabilitation is to enhance participation, and several factors may contribute to this, including individual abilities, task characteristics, and contextual factors. Rehabilitation clinicians, such as occupational therapists, often concentrate on improving client factors and alleviating performance skill impairments. There is a prevailing notion that by addressing impairments like contracture and spasticity, children's performance and participation can be enhanced. However, this belief may not always hold true, as other factors beyond impairments may also influence on the participation of children with CP.²² Parents of children undergoing rehabilitation programs that include group and community services have expressed a preference for more individualized services. However, they reported that the quality of services was not influenced by the type and intensity of the service. It remains undetermined to what extent parents of young children with cerebral palsy perceive physical therapy (PT) and occupational therapy (OT) interventions as familycentered and conducive to promoting their children's activity and participation.²³ A review of a pediatric rehabilitation program in the United States revealed that parents of children disabilities highlighted with socialization and belonging to a community as the most significant goals. Other research indicates that parents of children with disabilities view choice, independence, personal control, participation in ageappropriate activities, and interpersonal relationships as the most meaningful life outcomes for their children.²⁴

Need of the Study: As cerebral palsy (CP) is a congenital disorder due to abnormal brain development, often before birth which affects the movement, muscle tone or posture. As in CP the permanent damage occurs in the brain which required long term

exercise under the guidance of neurophysiotherapist or pediatric neurophysiotherapist but sometimes parents can't tolerate prolonged requirement of physiotherapy and they will not understand the importance of exercise in CP So, it is also important to know the parents and caregivers' opinion regarding exercise as they will only taking care for these types of children.

Aims of the Study: Explore perceptions about the value of exercise regimens for children with cerebral palsy.

MATERIALS AND METHODS

Source of data: Data were collected from parents or caregivers of children suffering from cerebral palsy (CP) in Surat city.

Study Design: Qualitative Study

Sample Size: By using G Power, we determined a sample size of 100.

Study Population: Parents and caregivers of children with cerebral palsy, providing insights into exercise program experiences.

Sampling Method: Convenient sampling. **Materials Used:**

- Pen
- Pencil
- Interview Based Questionnaire (In Google Form or on Paper)

Inclusion criterion

- Parents or legal guardians actively involved in the care of a child diagnosed with cerebral palsy.
- Child with any type of cerebral palsy.
- Children with cerebral palsy aged between 1 to 15 years.
- Parents or guardians who are receiving or not receiving an Exercise for their child with cerebral palsy.
- Individuals willing to share their experiences and perspectives through participation in a qualitative exploration.

Exclusion criterion

 Parents or guardians unable to provide informed consent due to legal or ethical considerations, such as custody disputes or legal restrictions

- Parents or guardians with a history of severe mental health conditions that may impact their ability to provide coherent and reliable responses.
- Child with CP but associated severe cardiovascular abnormality
- Parents or caregivers without a child diagnosed with cerebral palsy.
- Individuals who are unable to understand the questions and completely illiterate.
- Parents or caregivers with limited proficiency in the language.

Outcome Measures: Interview Based Ouestionnaire

Procedure of Study: • The study was done in two phases. The first phase included the development and validation of the questionnaire and the second phase included twenty-one questions regarding the importance of exercises according to parents of children with cerebral palsy.

Phase 1: Development and validation of the questionnaire.

- The questionnaire was divided into two sections. Section one consisted of sociodemographic details (age, contact details, education, occupation, and residence). Section two consisted of twenty-one questions regarding the importance of exercises according to parents of children with cerebral palsy. These questions focused on improving various aspects of the child's health, such as mobility, muscle strength, coordination, balance, social interaction and engagement, well-being, confidence.
- Content validation was performed for the questionnaire. Five experts. (experienced faculty in the area of neuro physiotherapy) were asked to rate the instrument
- Validation: items in terms of relevancy, clarity, and appropriateness to assess the face and content validity with the help of a 4-point ordinal scale for relevancy and clarity and a 2-point ordinal (yes and no) for appropriateness.

TABLE 1 CHECKING FOR RELEVANCY

Relevance				
1	Not Relevant			
2	Somewhat Relevant			
3	Quite Relevant			
4	Very Relevant			

TABLE 2 CHECKING FOR CLARITY

Clarity					
1	Not Clear				
2	Item Needs Some Revision				
3	Clear But Need Minor Revision				
4	Very Clear				

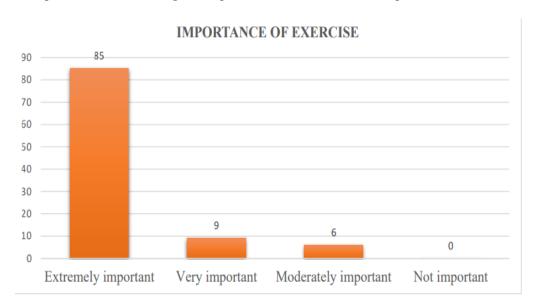
Phase 2: Twenty-one questions regarding the importance of exercises according to parents of children with cerebral palsy.

- A questionnaire was used to collect data to assess the awareness among parents of children with cerebral palsy, you would typically follow a structured procedure. The questionnaire consisted of 3 sections and a consent form.
- The questionnaire was divided into two sections.
- **Section One:** This section comprised socio-demographic details, including age, gender, contact details, education, occupation, and residence.
- Section Two: Consisting of twenty-one questions, this section focused on assessing the importance of exercises according to parents of children with cerebral palsy. These questions were designed to address various aspects of the child's health, including mobility, muscle strength, coordination, balance, social interaction and engagement, wellbeing, and confidence.
- **Section Three:** Prior to administering the questionnaire to parents and

caretakers of children with cerebral palsy, an informed consent process was conducted to ensure ethical considerations. **Participants** were provided with a detailed explanation of the research study, including its purpose, procedures, and potential benefits and risks. They were presented with a consent form outlining the study details, including voluntary participation, confidentiality measures, and the right to **Participants** withdraw. had the opportunity to ask questions and seek clarification before indicating agreement to participate. Emphasis was placed on the voluntary nature of participation, and participants assured that their decision to participate or decline would not affect their relationship with the researchers or their access to services. Signed consent forms were securely retained for documentation purposes in accordance with ethical guidelines.

RESULT

The data was statistically I analyzed using Microsoft Excel and IBM SPSS (version 20). The frequency and percentage were determined for the data (age, gender, education, occupation, and residence). The mean age of the child was 3.61 ± 1.9326801 years. 75% (75) of them were females. Only 13% of the participants were illiterate, 15% were unemployed, and most of the participants were businessman.



Graph 1: Parents and caregiver's opinions about value of and compliance with exercise:

Distribution of participants based on whether exercise is important in CP

85% of the participants were saying their opinion that exercise is extremely important for CP. 9% and 6% shows exercise is very important and moderately important for CP respectively. No one participants saying no importance of exercise in CP. So, almost all participants are saying that exercise is important for CP child. (Graph 1) In

univariate analysis, knowledge of the exercise importance in CP was associated with higher education of the study participants (p<0.05)

All participants have opinion about significant improvement and some improvement in mobility after exercise in CP child (Graph 2)

Graph 2: Distribution of participants based on positive changes in mobility after exercise

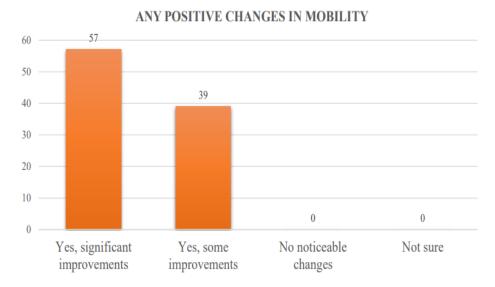
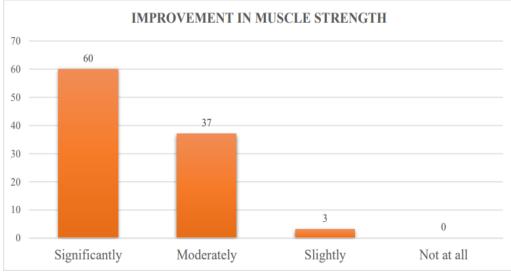


Table 3 Univariate analysis of variables influencing opinions about the value of and compliance with exercise regimen

Variable	Importance of exercise	Improvement in muscle strength	Confidence in exercise benefits	Improvement in coordination and balance	Relevance of professional guidance
Age:	0.86	0.001*	0.03*	0.01*	0.64
1-5 years (65)					
6-10 years (23)					
11-15 years (12)					
Education:	0.04*	0.08	0.10	0.50	0.02*
>10 Std. (54)					
<10 Std. (46)					

Chi-square was used for univariate analysis

 $\label{lem:continuous} \textbf{Graph 3: Distribution of participants based on improvement in muscle strength}$



About 60% of participants saying significant improvement in muscle strength after

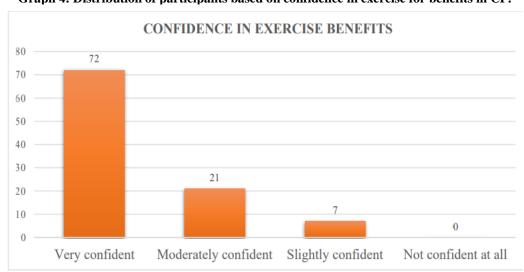
exercise but 37% and 3% participants have opinion that moderate and slightly

improvement through exercise in cp. (Graph 3) In univariate analysis, knowledge of the improvement in strength through exercise in CP was associated with age of the child (p<0.05)

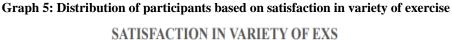
72% participants have much confidence on exercise for recovery in CP. Whereas 21% and 7% participants have moderate and slight confidence on exercise regarding benefits and recovery by it. (Graph 4) In univariate analysis, confidence regarding benefits through exercise in CP was associated with age of the child (p<0.05)

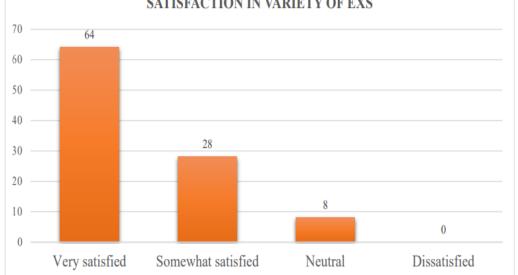
Here, 64% of participants are very satisfied with variety of exercise but 28% and 8% participants are somewhat satisfied and neutral respectively. (Graph 5)

59% of participants facing extremely challenge to incorporate the exercise 36% of participants facing moderate challenge to incorporate the exercise. Only 5% of participants facing slightly challenge to incorporate the exercise. (Graph 6) Which indicate larger number of parents feel so challenges while incorporating an exercise in child with CP.



Graph 4: Distribution of participants based on confidence in exercise for benefits in CP.



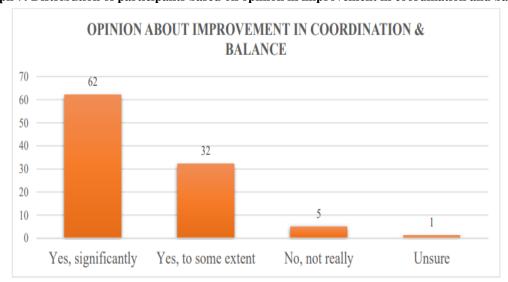


CHALLANGES TO INCORPORATE EXERCISE 70 59 60 50 36 40 30 20 10 0 Extremely Moderately Slightly challenging Not challenging

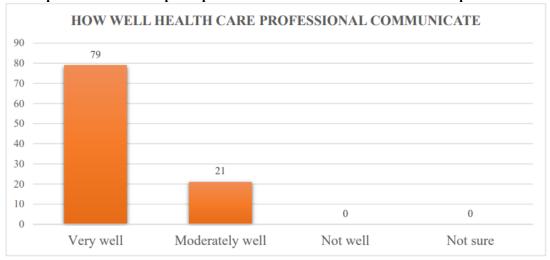
Graph 6: Distribution of participants based on Challenges faced by them for exercise

Graph 7: Distribution of participants based on opinion in improvement in coordination and balance

challenging



Graph 8: Distribution of participants based on communication of health care professionals



62% and 32% participants have opinion significant improvement about

challenging

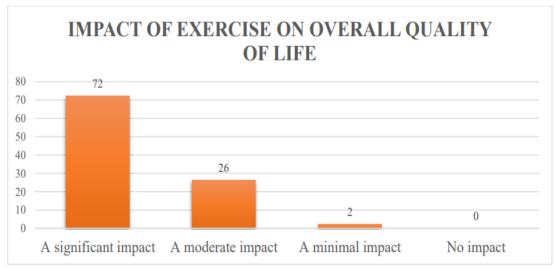
somewhat improvement in coordination and respectively. Whereas 5% balance of participants are saying that through exercise no improvement in balance and coordination. Only 1% participant is unsure about improvement in coordination and balance through the exercise in CP child (Graph 7) In univariate analysis, opinion about improvement in coordination and balance through exercise in CP was associated with age of the child (p<0.05) 79% participants feeling the communication of health care professionals for exercise is very well and 21% participants feeling the communication of health care professionals for exercise is moderately well. (Graph 8)



Graph 9: Distribution of participants based on relevance of professional guidance

71% of participants are heavily rely on professional guidance for exercise in child with CP. 25% Participants only moderately rely on exercise and 4% of participants slightly rely on exercise with child with CP.

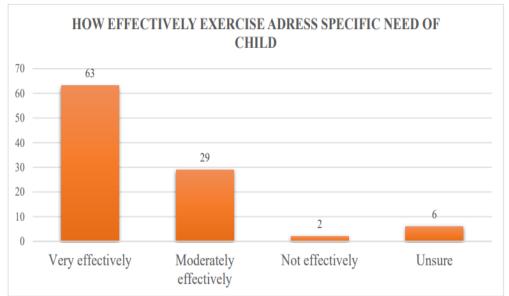
(Graph 9) In univariate analysis, opinion about relevance of professional guidance through exercise in CP was associated with education of the parent and caregiver. (p<0.05)



Graph 10: Distribution of participants based on impact of exercise on overall quality of life

72% of participants have opinion in significant impact on overall quality of life improvement through the exercise. 26% participants saying moderate impact of

exercise on overall quality of life by exercise. Only 2% of participant feeling minimal impact of exercise on child's overall quality of life. (Graph 10)



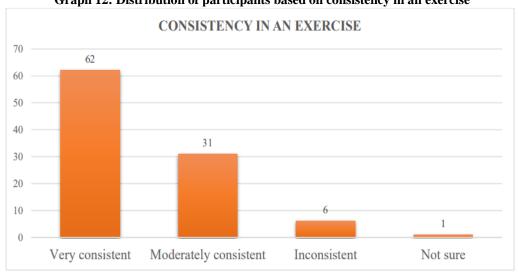
Graph 11: Distribution of participants based on effectiveness of exercise to address specific need of child

63% of participants feel that the exercise is effectively help to address the specific need of child with CP. 29% participants saying that the exercise is moderately effective to address the specific need of child. 2% and 6% participants feeling that exercise is not effective and not sure for its effectiveness respectively. (Graph 11)

62% participants are very consistent with exercise. 31% participants are moderately consistent with exercise. 6% of participants are inconsistent in exercise. 1% of

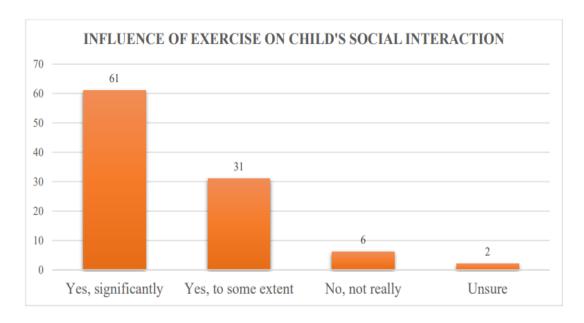
participant is not sure about the importance of exercise regarding its consistency. (Graph 12)

61% of participants are saying that exercise has significant influence on child's social interaction. 31% of participants have opinion in some extent an exercise will help in child's social interaction. 6% of participants saying that exercise don't have any effect on child's social interaction. 2% of participants are unsure about effect of exercise on child's social interaction. (Graph 13)

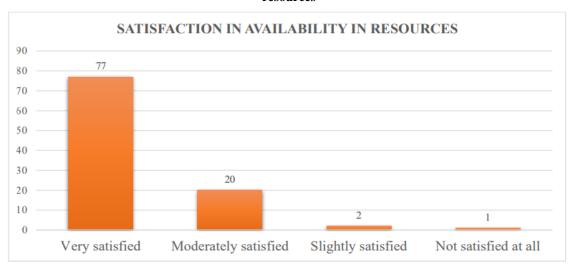


Graph 12: Distribution of participants based on consistency in an exercise

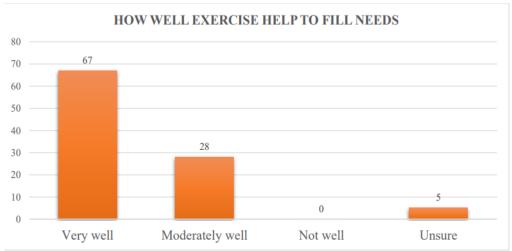
Graph 13: Distribution of participants based on exercise influence on child's social interaction.



Graph 14: Distribution of participants based on satisfaction in availability in resources



Graph 15: Distribution of participants based on how well exercise help to fill needs



77% of participants are very satisfied with availability in resources in exercise 20% of participants are moderately satisfied with availability in resources. 2% of participants are slightly satisfied with availability in resources. Only 1% of participant is not satisfied with availability of resources. (Graph 14)

67% of participants saying exercise will help very well to complete the need of ADL child with CP. 28% and 5% of participants saying exercise will help moderately well and unsure to complete the need of ADL child with CP respectively. (Graph 15)

DISCUSSION

Our qualitative study provides a unique perspective on the perceptions of caregivers of children with cerebral palsy (CP) regarding the value of and compliance with prescribed exercise regimens. perspective is particularly valuable in the context of the two studies mentioned here. One study highlights the need for a comprehensive review of exercise interventions for people with CP. The authors argue that such interventions should primarily focus on improving activity, participation, and quality of life. They also emphasize the need for more rigorous research methods, including randomized controlled trials (RCTs) and quasi-RCTs.²⁶ Another one study presents the first CPspecific physical activity and exercise recommendations. These recommendations are based on a comprehensive review of the literature, expert opinion, and extensive clinical experience. The authors argue that these recommendations can guide healthcare providers in prescribing exercise and physical activity for individuals with CP.²⁷ Let's further dissect the findings of our study. We found that caregivers' perceptions of the effectiveness of the exercise regimen had a significant influence on their compliance. This is an important finding because it suggests that the perceived effectiveness of an intervention can directly impact its success. Therefore, healthcare professionals should not only focus on the

technical aspects of the exercise regimen but also on how they communicate its benefits and potential outcomes to caregivers. In terms of the supporting study, it presents the first CP-specific physical activity recommendations. exercise These recommendations are based on comprehensive review of the literature, expert opinion, and extensive clinical experience. Our study complements this by providing real-world insights into how these recommendations are perceived implemented by caregivers. In the opposing study, the authors highlight the need for a comprehensive review of exercise interventions for people with CP. They argue that such interventions should primarily focus on improving activity, participation, and quality of life. Our study aligns with these objectives by providing insights into challenges real-world faced caregivers in adhering to these exercise regimens. This detailed discussion provides a comprehensive understanding of our study's contribution to the field and its implications for future research and practice. It highlights the complexity of managing CP and the importance of a holistic approach that considers the needs and challenges of both the individuals with CP and their caregivers. It also underscores the need for ongoing research to continue improving the quality of life for individuals with CP and their families.

CONCLUSION

Individuals were found to have a good understanding of the importance of exercise improve overall health, coordination, muscle strength, confidence, social interaction in Surat city. It is more significant with education of the parents and caregiver of child with cerebral palsy. This study showed that opinion about the value of and compliance with exercise regimen was equivalent to that of developed countries. To help these parents, it's important for healthcare providers to create exercise programs that address these barriers and involve parents in the process. More research is needed to find ways to make exercise programs more manageable and effective for families dealing with cerebral palsy.

Declaration by Authors

Ethical Approval: Approved Acknowledgement: None Source of Funding: None

Conflict of Interest: The authors declare no

conflict of interest.

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