

# Structured Care Protocol for Caregivers of Cerebral Palsy Cases: A Narrative Review

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## ABSTRACT

Structured care protocols such as Parent and Caregiver Training (PACT) frameworks have emerged as a promising strategy to address the substantial multidimensional burden experienced by caregivers of individuals with Cerebral Palsy (CP). Caregivers frequently face physical, emotional, social, and financial stressors, compounded by inadequate information, poor access to services, and limited structured support, particularly in low-resource settings. This narrative review synthesises current literature on the concept, characteristics, and impact of structured care protocols for CP caregivers, with specific emphasis on educational, psychosocial, skill-building, and resource-navigation components. A focused search of major databases identified studies and reviews describing caregiver-focused interventions, structured programs, and multidisciplinary models of care relevant to CP. The evidence indicates that PACT-type protocols can enhance caregiver knowledge, practical caregiving skills, self-efficacy, and perceived competence, which in turn are associated with reduced stress, lower caregiver burden, and improved quality of life for both caregivers and children. Key elements include systematic education on CP and home-based management, training in daily care and therapeutic activities, facilitation of access to medical, rehabilitative, social, and financial resources, and integration of psychosocial support and peer networks. Emerging work also highlights the potential of digital health platforms to improve scalability, continuity of support, and personalisation of these interventions across diverse sociocultural contexts. Nonetheless, gaps remain regarding standardised PACT models, culturally adapted content, and robust long-term outcome data, especially in developing countries. Future research should prioritise the development, implementation, and controlled evaluation of context-appropriate structured care protocols to optimise caregiver well-being and child outcomes in CP.

**Keywords:** Neurodevelopmental disorder, Parent and caregiver training, Psychosocial support, Quality of life

## INTRODUCTION

Cerebral Palsy is a complex and permanent neurodevelopmental disorder that primarily affects body movement and muscle coordination [1]. Originating from non-progressive disturbances in the developing foetal or infant brain, CP is a lifelong condition requiring ongoing care and management [1]. Individuals with CP often experience developmental deficits in cognition, language, behaviour, and motor skills, leading to functional limitations [2]. The multifaceted nature of CP means that affected individuals frequently need extensive support, impacting not only their lives but also those of their primary caregivers [3]. Caregivers of individuals with CP, often family members, undertake significant responsibilities that can lead to substantial burdens [4,5]. This caregiver burden is extensive, encompassing physical demands, emotional strain, social isolation, and financial pressures [6,7]. The sustained effort and sacrifices involved can adversely affect caregivers' physical and mental health, compromise their quality of life, and reduce their overall well-being [8,9]. Caregivers frequently report physical exhaustion, sleep deprivation, and chronic health issues, along with significant emotional distress such as anxiety, stress, and depression [6,10]. They may also face lifestyle disruptions and social isolation which are further exacerbated by the intensive caregiving tasks required, such as feeding, bathing, and mobility assistance [11].

Recognising these profound challenges, there is a clear and urgent need for robust support systems designed to alleviate this burden and empower caregivers [7,12]. In response to the identified needs of caregivers, the concept of Structured Care Protocols has emerged as a promising framework. PACTs are systematic and organised approaches developed to standardise the delivery of supportive care, with the goal of improving the well-being of caregivers [13]. These protocols typically integrate a range of components, including structured educational programs, psychosocial support

mechanisms, skill-building interventions to enhance caregiving capabilities, and guidance for navigating complex healthcare and social resources [14]. Such programs, including digital health interventions, have the potential to offer effective and accessible support to improve caregiver outcomes. This narrative review, aims to provide a comprehensive overview of existing literature pertaining to PACTs specifically developed for caregivers of individuals living with CP. This review will delve into the essential characteristics and components of such structured care protocols, exploring their documented impact on critical caregiver outcomes, including levels of stress, prevalence of burnout, overall quality of life, and self-efficacy in caregiving roles.

### Cerebral Palsy (CP) and Caregiver Burden

The CP is a chronic neurodevelopmental disorder that necessitates long-term care, imposing substantial challenges on caregivers [4]. The complexities of CP lead to a high degree of dependence in children, resulting in significant physical, emotional, social, and financial burdens for their caregivers [5]. Caring for a child with such functional limitations can severely impact the caregiver's physical and psychological well-being, often leading to diminished quality of life [15]. Caregivers of children with CP frequently experience chronic stress, fatigue, musculoskeletal pain, and an increased incidence of depression, underscoring the critical need for targeted support interventions [12]. This heightened vulnerability arises from the constant demands of primary caregiving, including feeding, locomotion, bathing, managing seizures, and attending numerous medical appointments [16]. Moreover, this intensive caregiving role often leads to reduced social interaction, professional limitations, and financial strain, which collectively contribute to the multidimensional burden experienced by these families [5,10]. Specifically, mothers of children with CP often assume the primary caregiving role and,

consequently, bear a disproportionately high burden, which can manifest as elevated depressive symptoms, poorer general health, and increased activity limitations compared to caregivers of healthy children [17]. The incessant demands of caregiving for children with CP, particularly complex cases, contribute significantly to increased levels of anxiety, stress, depression, and diminished self-efficacy among caregivers [7]. This emotional and physical toll often translates into a poorer quality of life for caregivers compared to those caring for children with other conditions, such as Down syndrome or autism [3]. Moreover, the intersection of socioeconomic factors, gender norms, and social stigma, particularly in low and middle-income settings, exacerbates this burden, leading to profound stress and depression among caregivers [6,18]. The functional limitations and chronic health issues associated with CP, such as mental retardation, speech impairment, and self-care deficits, further intensify caregiver workload and stress levels, making physical independence a difficult goal [19]. Many caregivers report feeling more disabled than the individuals they care for, experiencing chronic health problems themselves in addition to managing their child's ongoing needs [20]. The relentless nature of this care often leads to social isolation, as caregivers struggle to balance their responsibilities with personal needs and social engagement [21]. The ongoing strain can also lead to significant financial difficulties due to treatment costs and limitations on employment, further compounding their overall burden [6,21].

The magnitude of caregiver burden tends to increase as the child with CP grows older and their functional limitations become more pronounced [7]. For instance, mothers of children with CP often experience compromised care for their other children, leading to additional stress from perceived neglect or societal comparisons [6]. Moreover, mothers frequently report feelings of guilt, blame, and worry regarding their child's condition, often attributing the disability to their own actions during pregnancy or perceiving it as a personal failure of motherhood [22]. These profound emotional stressors, coupled with the physical and financial demands, contribute to a pervasive sense of isolation and decreased life satisfaction among caregivers [19]. This persistent distress often culminates in chronic health issues, including fibromyalgia, insomnia, and musculoskeletal pain, stemming from the intense physical and emotional labour involved in daily care [23].

### The Concept of Structured Care Protocols

These protocols aim to standardise and optimise the caregiving experience by providing clear guidelines and resources, thereby potentially mitigating the pervasive physical and psychological burdens identified in caregivers of children with CP [9,24]. Such structured approaches can address the inherent need for support services that extend beyond merely addressing the functional requirements of children with physical disabilities, aiming to bolster the overall well-being of their caregivers [7]. Specifically, these protocols focus on empowering caregivers through education and skill-building, which can lead to improved coping mechanisms and a reduction in reported stress levels [25,26]. They also serve to mitigate the adverse effects of limited access to basic amenities and specialised care services, particularly prevalent in developing nations, which exacerbates the vulnerability of caregiving families [27]. Moreover, these comprehensive protocols frequently incorporate psychological interventions and support groups, which have been shown to enhance caregivers' self-efficacy, emotional well-being, and adjustment to their demanding roles [6,7]. This holistic approach is crucial for addressing the multifaceted burden experienced by caregivers, encompassing not only the direct provision of care but also the emotional and social challenges they encounter [7]. A key aspect of these protocols involves the provision of informational support, which is critical for alleviating feelings of helplessness and improving a caregiver's capacity to effectively care for the child, thereby reducing their stress levels [6]. Furthermore,

these interventions often include financial assistance and respite care services, which are critical for alleviating economic strain and preventing burnout among caregivers [18,28]. By integrating such comprehensive support, PACTs aim to foster a more sustainable care environment, ultimately enhancing the quality of life for both the child with cerebral palsy and their primary caregiver [12,29]. The integration of educational, psychosocial, and economic support within structured care protocols is paramount, as neuroplasticity theory emphasises the continuous practice of functional activities in children with CP, which necessitates sustained, informed home-based care by caregivers for optimal functional outcomes [7]. This framework can not only facilitate the acquisition of practical caregiving skills but also addresses the psychological and social determinants of caregiver well-being, which are critical for sustaining long-term care [30,31]. A lower level of caregiver education, often linked to the "caregiver martyr syndrome," directly correlates with reduced employment opportunities and diminished financial stability, intensifying the caregiving burden [32]. This highlights the critical importance of incorporating educational and vocational support within PACTs to empower caregivers and mitigate the adverse financial consequences associated with their demanding roles [33]. PACTs can help in developing parent navigators and peer support groups that can address the existing gap in resources by connecting families with knowledgeable individuals who can guide them through the intricate landscape of CP care, enabling them to advocate effectively for their children's needs [34].

### Characteristics of Structured Care Protocols for Caregivers of Individuals with Cerebral Palsy (CP)

These protocols typically integrate multidisciplinary approaches, encompassing medical, psychological, social, and financial support components tailored to the complex needs of caregivers [35].

**Educational components:** A crucial aspect of these protocols involves disseminating comprehensive information regarding cerebral palsy, its management, and available support systems, which significantly reduces caregiver stress and enhances their sense of control [36]. This educational provision extends to practical training in therapeutic exercises and daily care routines, thereby equipping caregivers with the competencies necessary for effective home-based management [31]. Additionally, knowledge dissemination about CP and associated care improves caregivers' self-efficacy, enabling them to make informed decisions and better navigate the healthcare system [8]. The educational components frequently incorporate training on behavioural management strategies, empowering caregivers to address challenging behaviours effectively and promote positive interactions within the family unit. Such formalisation can include assigning care coordinators or transition navigators to families, thereby alleviating stress and confusion during critical periods [37]. Caregivers of children with complex neurodisabilities, including CP, frequently express a need for up-to-date information, particularly around the time of diagnosis, to enhance their understanding of the condition and available services [36]. This foundational knowledge is critical for empowering caregivers to participate actively in shared decision-making processes and to advocate effectively for their child's needs within the complex healthcare landscape [36]. Effective educational programs also foster an open exchange of information, respectful and supportive care, and strong partnerships between parents and healthcare professionals. This emphasis on education is crucial, as caregivers often report difficulties understanding the implications of a cerebral palsy diagnosis and navigating the complexities of associated co-morbidities [36].

**Psychosocial support:** Psychosocial Support is a foundational characteristic designed to comprehensively address the emotional, mental, and social challenges faced by caregivers. These protocols aim to standardise and optimise the caregiving experience by

providing structured support mechanisms to mitigate the pervasive physical and psychological burdens [9,24]. Specifically, PACTs frequently integrate psychological interventions and support groups into their design [6,7]. The goal of these components is to enhance caregivers' self-efficacy, improve their emotional well-being, and facilitate their adjustment to the demanding nature of their roles. Psychological interventions can help caregivers develop coping strategies for stress, anxiety, and depression, while support groups offer a vital platform for connection, shared experiences, and mutual encouragement among individuals facing similar caregiving journeys [6,7]. This holistic approach acknowledges that addressing the psychological and social needs of caregivers is paramount to sustaining their well-being and, by extension, ensuring high-quality care for individuals with CP.

**Skill-building interventions:** Skill-Building Interventions are a crucial characteristic aimed at equipping caregivers with the practical abilities and confidence needed to navigate the complex demands of caregiving. While the specific subsection "Skill-Building Interventions" in your document is currently empty, the broader context of PACTs emphasises the importance of empowering caregivers through education and skill enhancement [38]. These interventions typically encompass practical training in areas such as therapeutic exercises, daily care routines, and managing the child's specific needs. For example, caregivers might receive training on proper positioning, feeding techniques, mobility assistance, and behavioural management strategies [39]. By developing these concrete skills, caregivers can enhance their self-efficacy (their belief in their own capability to perform tasks) effectively and improve their overall competence, and significantly reduce the stress associated with their caregiving responsibilities [7,8,39,40]. This proactive approach not only benefits the caregivers' well-being but also leads to improved functional outcomes for the children with CP, as empowered and skilled caregivers are better equipped to implement consistent and effective home-based care [31]. Furthermore, these interventions often incorporate psychoeducational frameworks to provide caregivers with coping mechanisms and strategies to manage the emotional and psychological burdens associated with their demanding roles [41].

**Resource navigation:** Resource navigation is a critical characteristic aimed at guiding caregivers through the often complex landscape of available support, services, and information. It involves:

- Identifying and accessing services: Helping caregivers locate and utilise medical, therapeutic, educational, financial, and social services relevant to the child's needs and the family's situation.
- Understanding complex systems: Guiding caregivers through healthcare systems, insurance processes, educational special needs programs, and government assistance programs, which can be overwhelming and difficult to navigate on their own.
- Information dissemination: Ensuring caregivers receive timely and accurate information about CP, treatment options, prognosis, and available community resources.
- Advocacy: Empowering caregivers to effectively advocate for their child's needs and rights within various institutional settings.

The goal of integrating resource navigation into PACTs is to reduce caregiver stress by streamlining access to necessary support, thereby alleviating feelings of helplessness and improving their capacity to effectively care for the child [6]. This structured guidance helps caregivers make informed decisions and ensures they are connected to the crucial support networks that can significantly improve their overall well-being and the quality of life for the individual with CP. Moreover, effective resource navigation can significantly mitigate caregiver burden by connecting them with formal and informal support networks, thereby fostering resilience and preventing social isolation [15]. Caregivers of children with CP often experience significant stress due to the demanding nature

of their responsibilities, including managing daily needs, medical appointments, and interventions [16].

## Impact of PACT on Caregiver Outcomes

Structured care protocols are designed to significantly impact and improve various outcomes for caregivers of individuals with CP by providing a systematic framework of support. The overarching goal of PACTs is to mitigate the adverse effects of caregiving, enhance caregiver competence, and ultimately foster a better quality of life for both the caregiver and the individual with CP [15]. Here's a detailed explanation of their impact on specific caregiver outcomes:

**Caregiver stress and burnout:** The PACTs are specifically designed to reduce caregiver stress and burnout. By empowering caregivers through education, skill-building, and informational support, these protocols lead to improved coping mechanisms and a reduction in reported stress levels. The provision of informational support is critical for alleviating feelings of helplessness and improving a caregiver's capacity to effectively care for the child, thereby directly reducing their stress levels [6]. Additionally, the incorporation of psychological interventions and support groups within PACTs helps caregivers develop strategies to manage the stress, anxiety, and depression that often accompany their demanding roles [6,7]. By proactively addressing these psychological burdens, PACTs contribute to a more sustainable caregiving experience and help prevent the onset of burnout [7]. Formal support systems integrated into PACTs contribute significantly to caregivers' effective coping with the multifaceted challenges of caring for children with CP, which often include physical strain, work-related difficulties, and social stigma [10].

**Quality of life for caregivers:** Caring for individuals with CP often leads to significant caregiver burden, affecting various aspects of their lives. This burden is a multidimensional response to the physical, emotional, psychological, social, and financial stressors associated with the caregiving experience [5]. Studies consistently demonstrate that this high level of burden detrimentally impacts caregivers' mental and physical health, family dynamics, and social interactions, frequently resulting in a lower quality of care and unmet patient needs [5]. Consequently, PACTs address these challenges by providing structured interventions aimed at enhancing caregiver well-being across physical, psychological, social, and environmental domains, as defined by the World Health Organisation (WHO) [4]. By addressing the multidimensional burdens: physical, emotional, psychological, social, and financial that diminish caregiver well-being, PACTs strive to create a more sustainable care environment. The comprehensive support offered, including psychosocial interventions and access to resources, aims to enhance caregivers' emotional well-being and their adjustment to demanding roles, thereby fostering a higher quality of life for the caregiver and the family unit [15].

## Key Areas of Caregiver Burden in CP

**Physical burden:** Caregivers frequently experience physical exhaustion, sleep deprivation, and chronic health issues such as back pain, due to the demanding tasks involved in caring for a child with CP [10,16,42]. These tasks often include feeding, bathing, lifting, and assisting with mobility [16].

**Psychological and emotional burden:** The emotional strain on caregivers is substantial, with high rates of stress, anxiety, and depression [6,8]. The constant demands, coupled with the child's behavioural problems and frequent need for acute medical care, can significantly impact caregivers' mental health [8]. This can lead to feelings of being overwhelmed, sadness, and a decline in overall mental well-being [43].

**Social burden:** Caregivers often face social isolation, lifestyle disruptions, and reduced participation in social activities [3,16,33]. They may have to give up jobs or leisure activities, leading to confinement and a decline in their social life [11,16]. Social stigma,

discrimination, and a lack of community support can further exacerbate this isolation [6,24,44].

**Financial burden:** Caring for a child with CP involves considerable financial strain due to the need for extensive care, rehabilitation training, and specialised services [5,20]. Many families incur significant out-of-pocket costs, and caregivers may experience reduced income or job loss due to their caregiving responsibilities [45,46]. This financial pressure is a major contributor to the overall burden [5].

**Overall impact:** The cumulative effect of these burdens can lead to a decline in the caregiver's quality of life and negatively impact family functions [5]. The quality of care provided to children with CP also depends heavily on the well-being of their caregivers [3]. Studies have highlighted that factors such as the child's age, the severity of their disability, and the caregiver's occupation can predict the level of burden experienced [4,47]. In summary, the caregiving experience for individuals with CP is profoundly challenging, necessitating comprehensive support systems to mitigate the diverse burdens placed on caregivers.

## CAREGIVER COMPETENCE AND SELF-EFFICACY

Caregiver competence and self-efficacy are crucial constructs in understanding the experiences and effectiveness of individuals caring for those with chronic conditions, particularly children with CP. These concepts are often intertwined, with self-efficacy playing a significant role in a caregiver's perceived and actual competence.

### Caregiver Self-efficacy

Caregiver self-efficacy refers to a caregiver's belief in their own capability to successfully perform caregiving tasks and manage various challenges associated with the care recipient's condition [48]. It reflects confidence in one's ability to cope with the demands of caregiving, examine situations, and manage negative thoughts and feelings that arise from caregiving activities [49].

Key aspects of self-efficacy in caregiving include:

- **Confidence in daily tasks:** This involves the belief in one's ability to handle routine care, such as feeding, bathing, and assisting with mobility [49].
- **Coping mechanisms:** Self-efficacy acts as a coping mechanism, empowering caregivers to deal with the difficulties and stress inherent in their role [49,50].
- **Managing challenging behaviours:** For caregivers of individuals with developmental disabilities, this can involve confidence in responding to disruptive behaviours [51].
- **Obtaining support:** The belief in one's ability to seek and utilise respite and other support resources is also a component [51].
- **Problem-solving:** Confidence in problem-solving related to caregiving tasks and situations [52]. Higher levels of caregiver self-efficacy are associated with better physical and mental health for caregivers, improved relationships, and greater satisfaction in their personal lives [50]. Conversely, low self-efficacy is linked to higher caregiver burden, poorer physical and psychological health, and reduced quality of life [4,7].

### Caregiver Competence

Caregiver competence can be understood as the possession of the necessary knowledge, skills, and abilities to provide effective and appropriate care. It encompasses both the practical application of skills and the understanding of the care recipient's needs. While self-efficacy is about belief in one's abilities, competence is about the actual capabilities and effectiveness in carrying out those abilities. Components of caregiver competence include:

- **Knowledge:** Understanding the specific needs, strengths, and weaknesses of the person being cared for, as well as

knowledge about the condition (e.g., Cerebral Palsy) and available resources [49,53]. Caregivers in some regions have shown inadequate knowledge regarding CP and its care, highlighting a need for educational programs [49].

- **Skills:** Practical abilities required for daily care, therapeutic activities, and navigating healthcare systems. This includes organisational skills for scheduling medication, tactical skills to anticipate needs, and recruiting skills to find and coordinate resources [48].
- **Value:** Recognising and valuing their experience and role as caregivers, and being open to the needs of the present [53].
- **Patience:** Cultivating tolerance, self-control, and the ability to find meaning and growth through their caregiving journey [53]. Importance in CP caregiving

For caregivers of children with CP, high competence and self-efficacy are vital for several reasons:

**Mitigating burden:** Increased self-efficacy helps in managing the significant physical, emotional, and financial burdens associated with CP care [4,54]. Caregivers with higher self-efficacy often report lower stress and better quality of life [49,55].

**Improved child outcomes:** Parental self-efficacy has implications for parenting practices and the child's adjustment [56]. When caregivers feel competent and confident, they are better equipped to implement therapeutic activities and support the child's development [31,57].

**Empowerment:** Fostering self-efficacy can empower caregivers, leading to improved well-being for the entire family [55].

**Effective Intervention:** Interventions designed to enhance caregiver skills and knowledge directly contribute to their competence and, subsequently, their self-efficacy [40,58]. Educational programs have been shown to increase caregivers' knowledge of CP, which is crucial for effective caregiving adjustment [7].

### Factors Influencing Self-Efficacy and Competence

**Child's dependency level:** Caregivers of less dependent children often report higher self-efficacy, while those caring for severely dependent children may experience lower self-efficacy [4,54].

**Interventions and training:** Structured programs, parenting interventions, and skills training can significantly increase parental self-efficacy and capabilities [57,58].

**Social support:** Perceived social support is related to self-efficacy [59].

**Knowledge acquisition:** Educational programs that enhance caregivers' knowledge about CP and care techniques can improve their confidence and ability to manage demands [7,49].

**Psychological factors:** Attitudes towards collaboration with professionals can also influence self-efficacy [59].

In essence, promoting caregiver competence and self-efficacy through targeted interventions and supportive environments is paramount for enhancing the well-being of caregivers and, by extension, improving the quality of life and outcomes for children with CP.

### Gaps and Limitations in Existing Literature

Here's a detailed explanation of each identified gap:

**Methodological heterogeneity:** A significant challenge in the existing literature is the inconsistency in research methodologies employed across studies. This heterogeneity makes it difficult to compare findings directly, synthesise results, and draw universally applicable conclusions. Differences in study design, outcome measures, participant recruitment, and intervention delivery can obscure the true impact of PACTs and prevent the identification of the most effective components.

**Longitudinal studies:** There is a notable scarcity of longitudinal studies. Many studies tend to be cross-sectional or have short follow-up periods. This lack of long-term research means that the sustained impact of PACTs on caregiver outcomes over extended periods is not well understood. Longitudinal studies are crucial for assessing the durability of intervention effects, identifying potential long-term benefits or challenges, and understanding how caregiver needs evolve over time.

**Cross-cultural perspectives:** The existing literature often lacks diverse cross-cultural perspectives. Research tends to be concentrated in specific geographical regions or cultural contexts, which limits the generalisability of findings. Caregiving experiences, available resources, and cultural norms surrounding disability can vary significantly across different societies. Therefore, a more inclusive research approach is needed to develop PACTs that are culturally sensitive and effective in various global contexts.

**Diverse caregiver populations:** Finally, there is a limitation regarding the diversity of caregiver populations included in studies. Research often focuses predominantly on mothers as primary caregivers. However, fathers, grandparents, siblings, and other informal caregivers also play vital roles and experience unique challenges. To create truly comprehensive and equitable PACTs, future research must expand its focus to include and understand the experiences and needs of this broader spectrum of caregivers.

**Recommendations for future research and practice:** To address the aforementioned limitations, future research should prioritise robust methodological approaches, including longitudinal designs and randomised controlled trials, to establish causality and long-term efficacy. Additionally, studies should incorporate diverse caregiver populations, including fathers and extended family members, to provide a more holistic understanding of caregiving dynamics and needs. Furthermore, investigations into culturally adapted interventions are crucial to ensure relevance and effectiveness across varied social and economic contexts. Exploration of funding models that facilitate sustainable interventions and fair compensation for facilitators is also warranted. Finally, given the diverse cultural landscapes, future research should also rigorously examine how autism stigma manifests and impacts caregiver mental health in various socio-cultural settings, especially those not extensively studied.

**Development of standardised PACTs:** The development of standardised protocols is essential to ensure consistent quality and effectiveness across different clinical settings and caregiver populations. These standardised protocols should incorporate validated outcome measures for rigorous evaluation and be adaptable to various cultural and socioeconomic contexts. Such standardisation would facilitate direct comparisons between studies, contributing to a more cohesive body of evidence regarding PACT efficacy. Furthermore, the exploration of culturally competent facilitators and multilingual materials is crucial for improving inclusivity and trust within these standardised frameworks. This would involve integrating culturally sensitive communication strategies and resource provision to effectively meet the diverse needs of caregivers. Moreover, the incorporation of community-based participatory research approaches could ensure that PACTs are co-designed with caregivers, thereby enhancing their relevance and acceptability.

**Implementation and evaluation in varied settings:** To ensure wider applicability, PACTs must be rigorously implemented and evaluated in diverse healthcare settings, including low-resource environments and community-based programs. This expanded implementation necessitates the development of context-specific adaptations to address unique challenges and leverage existing community assets. Moreover, robust evaluations, including process evaluations, are crucial to understand the mechanisms of impact and identify barriers and facilitators to successful implementation. This would involve assessing fidelity to the intervention model

while also allowing for flexibility to accommodate local cultural nuances and resource limitations. This integration may necessitate multidisciplinary collaborations and strategic partnerships with community organisations to ensure comprehensive and accessible support for caregivers.

**Incorporation of digital health solutions:** The integration of digital health solutions, such as mobile applications and telehealth platforms, presents a significant opportunity to enhance the accessibility, scalability, and personalisation of PACTs for caregivers. These technologies can deliver psychoeducation, facilitate peer support, and offer remote consultations, thereby overcoming geographical and logistical barriers to access [60]. Furthermore, digital platforms can enable data collection for continuous monitoring and evaluation of intervention effectiveness, allowing for adaptive adjustments to care plans and content. Such solutions can also incorporate artificial intelligence to personalise content delivery and provide tailored support based on individual caregiver needs and progress, thus optimising engagement and outcomes. However, careful consideration of digital literacy, cultural appropriateness, and data privacy is essential to ensure equitable access and maximise the benefits of these technological advancements for all caregivers.

**Policy implications:** The findings from such research are critical for informing policy decisions that support the widespread adoption and sustainable implementation of digitally-enabled PACTs, particularly in a post-pandemic landscape where mental health support for caregivers remains a significant need. Policymakers should prioritise funding for research into digital health interventions for caregivers, particularly for understudied mental health conditions and marginalised population. Additionally, policies should address the digital divide to ensure equitable access to these technologies for all caregivers, irrespective of their socioeconomic status or geographic location.

## CONCLUSION(S)

This narrative review underscores the critical role of structured care protocols in enhancing the well-being and efficacy of caregivers for individuals with CP. The synthesis of current literature highlights the multifaceted challenges faced by these caregivers, ranging from informational deficits to significant financial and emotional burdens, thereby underscoring the urgent need for comprehensive support systems. This review also delineates the potential of PACTs to mitigate these challenges by providing structured guidance, fostering skill development, and facilitating access to essential resources, including through the strategic integration of digital health solutions. Future research should focus on developing and evaluating PACTs that are tailored to diverse cultural contexts and socioeconomic strata, leveraging digital health technologies to improve accessibility and engagement. Further investigation is required to ascertain the long-term impact of these interventions on caregiver mental health and patient outcomes, particularly in low-resource settings where informal caregiving is prevalent. Moreover, understanding the specific needs and preferences of caregivers within these contexts is crucial for designing interventions that are both effective and sustainable.

## REFERENCES

- [1] Miller F. Cerebral Palsy [Internet]. 2005 [cited 2025 Nov]. Available from: [https://openlibrary.org/books/OL7444328M/Cerebral\\_Palsy](https://openlibrary.org/books/OL7444328M/Cerebral_Palsy).
- [2] Ogundele M, Morton M. Classification, prevalence and integrated care for neurodevelopmental and child mental health disorders: A brief overview for paediatricians. *World J Clin Pediatr*. 2022;11(2):120-35.
- [3] Liu F, Zhang R, Cui C, Zhou H. Care burden and quality of life among family caregivers of children with cerebral palsy in China: The mediating roles of social support and coping styles. *BMC Public Health*. 2025;25(1):506.
- [4] Taleb MYMA, Sayed M, El Ghamry R, Hashem R, El Shamy H, Mansour O. Burden, self-efficacy, and quality of life among caregivers of cerebral palsy children at the National Institute of Neuromotor System. *Middle East Current Psychiatry*. 2025;32. [cited 2025 Nov]. Available from: <https://doi.org/10.1186/s43045-025-00577-z>.

- [5] Liu F, Shen Q, Huang M, Zhou H. Factors associated with caregiver burden among family caregivers of children with cerebral palsy: A systematic review. *BMJ Open*. 2023;13(4):e065215.
- [6] Kannappan V, Sekar P, Sruthi S, Gopichandran V. Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*. 2020;20(1):645.
- [7] Dambi JM, Jelsma J, Mlambo T, Chiwaridzo M, Tadyanemhandu C, Chikwanha MT, et al. A critical evaluation of the effectiveness of interventions for improving the well-being of caregivers of children with cerebral palsy: A systematic review protocol. *Syst Rev*. 2016;5(1):112. Available from: <https://doi.org/10.1186/s13643-016-0287-4>.
- [8] Kouther DA, Shakir MO, Alhumaidah RA, Jamaluddin HA, Jaha AY, Alshumrani MJ, et al. Factors influencing the mental health of caregivers of children with cerebral palsy. *Front Pediatr*. 2022;10:920744. Available from: <https://doi.org/10.3389/fped.2022.920744>.
- [9] Almeida MF de, Mello S, Zonta MB, Crippa AC de S. Cerebral palsy and sleep: Nonpharmacological treatment and impact on the life of caregivers - An integrative review. *Arq Neuropsiquiatr*. 2024;82(3):01-09. Available from: <https://doi.org/10.1055/s-0044-1781464>.
- [10] Kisinna AA, Ohene LA, Attafuah PYA. Family caregivers' burden and coping with caring for children with cerebral palsy: A qualitative study in a low-resourced context, Ghana. *Child Care Health Dev*. 2025;51(4):e70141. Available from: <https://doi.org/10.1111/cch.70141>.
- [11] Eyong K, Ekanem E, Asindi AA. Challenges of care givers of children with cerebral palsy in a developing country. *International Journal of Contemporary Pediatrics*. 2017;4(4):1128. Available from: <https://doi.org/10.18203/2349-3291.ijcp20172656>.
- [12] Khoza SB, Chetty V, Chetty L. Support programmes for caregivers of children with cerebral palsy: A scoping review protocol. *Research Square*. 2024. [cited 2025 Sep]. Available from: <https://doi.org/10.21203/rs.3.rs-3937830/v1>.
- [13] Teixeira FG, Godinho C, Fernandes JB. Personalized care and treatment compliance in chronic conditions. *J Pers Med*. 2022;12(737):01-03. Available from: <https://doi.org/10.3390/books978-3-0365-4241-6>.
- [14] Corry M, Neenan K, Brabyn S, Sheaf G, Smith V. Telephone interventions, delivered by healthcare professionals, for providing education and psychosocial support for informal caregivers of adults with diagnosed illnesses. *Cochrane Database Syst Rev*. 2019;5(5): CD012533. Available from: <https://doi.org/10.1002/14651858.cd012533.pub2>.
- [15] Poojari DP, Umakanth S, Maiya GA, Rao BK, Khurana S, Kumaran D S, et al. Effect of family-centered care interventions on well-being of caregivers of children with cerebral palsy: A systematic review. *F1000Res*. 2024;12:790. Available from: <https://doi.org/10.12688/f1000research.133314.1>.
- [16] Dlamini MD, Chang Y, Nguyen TTB. Caregivers' experiences of having a child with cerebral palsy: A meta-synthesis. *J Pediatr Nurs*. 2023;73:157-68. Available from: <https://doi.org/10.1016/j.pedn.2023.08.026>.
- [17] Park E. Psychometric properties of the caregiving difficulty scale in mothers of children with cerebral palsy. *BMC Neurol*. 2023;23:237. Available from: <https://doi.org/10.1186/s12883-023-03264-w>.
- [18] Vadivelan K, Sekar P, Sru SS, Gopichandran V. Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*. 2020;20(1):645. Available from: <https://doi.org/10.21203/rs.3.rs-16838/v1>.
- [19] Özden F, Arik AF, Özkeskin M, Bakırhan S. The relationship between caregiver workload and stress levels with clinical symptom severity in cerebral palsy. *International Journal of Disabilities Sports and Health Sciences*. 2021;4(1):38-44. Available from: <https://doi.org/10.33438/ijds.833840>.
- [20] Marian S. Impact of Cerebral Palsy on Parents and Families [Internet]. In: *IntechOpen eBooks*. IntechOpen; 2023. [cited 2025 Oct]. Available from: <https://doi.org/10.5772/intechopen.106470>.
- [21] Alam FH, Berry KIE, Sweelam RKM, Arrab MM, Shehata HSh. Effectiveness of acceptance and commitment based intervention on stress, future anxiety and quality of life among mothers of children with cerebral palsy. *International Egyptian Journal of Nursing Sciences and Research*. 2023;3(2):281-306. Available from: <https://doi.org/10.21608/ejnsr.2023.277922>.
- [22] Olayinka-Aliu DA. Efficacy of acceptance and commitment therapy on psychological health and inflexibility among mothers of children with cerebral palsy. *Tazkiya Journal of Psychology*. 2022;10(2):165-77. Available from: <https://doi.org/10.15408/tazkiya.v10i2.23175>.
- [23] Karibel IA, Aksoy MK, YENİ M. Fibromyalgia syndrome in mothers of children with cerebral palsy and its relationship with caregiver burden: A cross-sectional study. *The European Research Journal*. 2023;10(1):59-69. Available from: <https://doi.org/10.18621/eurj.1292729>.
- [24] Dambi JM, Jelsma J, Mlambo T. Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers. *Afr J Disabil*. 2015;4(1):168. Available from: <https://doi.org/10.4102/ajod.v4i1.168>.
- [25] Hartley J, Bluebond-Langner M, Candy B, Downie J, Henderson EM. The physical health of caregivers of children with life-limiting conditions: A systematic review. *Pediatrics*. 2021;148(2):e2020014423. Available from: <https://doi.org/10.1542/peds.2020-014423>.
- [26] Andrade MMG de, Sá FE de, Frota LM da CP, Cardoso KVV, Carleial GM de A. Interventions of health education in mothers of children with cerebral palsy. *J Hum Growth Dev*. 2017;27(2):175. Available from: <https://doi.org/10.7322/jhgd.126857>.
- [27] Adıgüzel H, Kırmacı ZİK, Erel S, Ergün N. Turkish version of caregiver difficulties scale for the children with cerebral palsy: A study of validity and reliability. *Medical Records*. 2024;6(1):124-31. Available from: <https://doi.org/10.37990/medr.1375252>.
- [28] Peng M, Lu YF. Mothers' challenges and experiences of children with cerebral palsy: A qualitative meta-synthesis. *Frontiers of Nursing*. 2024;11(2):169. Available from: <https://doi.org/10.2478/fo-n-2024-0018>.
- [29] Byrne M, Hurley DA, Daly L, Cunningham C. Health status of caregivers of children with cerebral palsy. *Child Care Health Dev*. 2010 Sep;36(5):696-702. Available from: <https://doi.org/10.1111/j.1365-2214.2009.01047.x>.
- [30] Bakuwa TC, Saloojee G, Slemming W. Facilitators and barriers to the implementation of a caregiver-led training programme for caregivers of children with cerebral palsy in rural Malawi. *bioRxiv (Cold Spring Harbor Laboratory)*. 2025. [cited 2025 Oct]. Available from: <https://doi.org/10.1101/2025.10.22.25338418>.
- [31] Magidigidi-Mathiso L, Frantz J, Filles GC. Caregiver capabilities: Healthcare interventions for children with developmental disabilities. *Afr J Disabil*. 2025;14:1563. Available from: <https://doi.org/10.4102/ajod.v14i0.1563>.
- [32] Ferreira ACFM, Eveloff RJ, Freire M, Santos MTBR. Clinical and inflammatory factors influencing constipation and quality of life in cerebral palsy. *medRxiv (Cold Spring Harbor Laboratory)*. 2019. [cited 2025 Jan]. Available from: <https://doi.org/10.1101/19011296>.
- [33] Mwinbam MM, Suglo JN, Kukeba MW. Family caregivers' experience of care with a child with cerebral palsy: The lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana. *BMJ Paediatr Open*. 2023;7(1):e001807. Available from: <https://doi.org/10.1136/bmjpo-2022-001807>.
- [34] Shierk A, Clegg NJ, Fulton DR, Delgado MR, Hunt VV, Bettger JP, et al. Multi-collaborator engagement to identify research priorities for early intervention in cerebral palsy. *J Clin Med*. 2025 Oct 26;14(21):7592. Doi: 10.3390/jcm14217592.
- [35] Eloreidi RMD, Kehyayan V, Kalu F, Thornton L. Needs of caregivers of children with cerebral palsy: A literature review. *Journal of Nursing Education and Practice*. 2021;11(9):23-28. [cited 2025 Nov]. Available from: <https://doi.org/10.5430/jnep.v11n9p23>.
- [36] Prest K, Wilson E, Vassiliadou I, Ali S, Lakhanpaul M, Morris C, et al. What are the priority needs for those caring for children and young people with complex neurodisability within an ethnically diverse UK context? - The feasibility phase of the ENCOMPASS study. *medRxiv (Cold Spring Harbor Laboratory)*. 2023. [cited 2025 Oct]. Available from: <https://doi.org/10.1101/2023.03.23.23287248>.
- [37] Mitchell D, Shlobin NA, Winterhalter EJ, Lam S, Raskin JS. Gaps in transitional care to adulthood for patients with cerebral palsy: A systematic review. *Childs Nerv Syst*. 2023;39(11):3083-3101. Available from: <https://doi.org/10.1007/s00381-023-06080-2>.
- [38] Bakuwa TC, Saloojee G, Slemming W. Caregiver-led versus therapist-led training programme for caregivers of children with cerebral palsy in rural Malawi: A feasibility randomised controlled trial. *Research Square*. 2025;01-16. [cited 2025 Oct]. Available from: <https://doi.org/10.21203/rs.3.rs-6952526/v1>.
- [39] Nobakht Z, Rassafiani M, Hosseini SA, Hosseinzadeh S. A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial. *Res Dev Disabil*. 2020;105:103731. Available from: <https://doi.org/10.1016/j.ridd.2020.103731>.
- [40] Salomone E, Pacione L, Shire S, Brown FL, Reichow B, Servil C. Development of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays. *Front Psychiatry*. 2019;10:769. Available from: <https://doi.org/10.3389/fpsy.2019.00769>.
- [41] Alibakhshi H, Davoudi Z, Damirchi N, Kavian M, Siminghalam M. The impact of group psychoeducation for mothers of children with cerebral palsy: A randomized controlled trial. *Middle East J Rehabil Health Stud*. 2024;12(2):e146484. Available from: <https://doi.org/10.5812/mejr-146484>.
- [42] Manyuma D, Maluleke M, Raliphaswa NS, Masutha TC, Ranganeni ME, Thabathi TE, et al. Title: Caring for children with cerebral palsy: A challenge to caregivers in rural areas of South Africa. *Children (Basel)*. 2023;10(3):440. Available from: <https://doi.org/10.3390/children10030440>.
- [43] Ying K, Rostenberghe HV, Kuan G, Yusoff MHAM, Ali SH, Yaacob NS. Health-related quality of life and family functioning of primary caregivers of children with cerebral palsy in Malaysia. *Int J Environ Res Public Health*. 2021;18(5):2351. Available from: <https://doi.org/10.3390/ijerph18052351>.
- [44] Morilla CM, Caldas CACT, Scarpellini ACAV, Santos PL dos. Family resources and promotion of development of children with cerebral palsy. *J Hum Growth Dev*. 2017;27(2):166-74. Available from: <https://doi.org/10.7322/jhgd.122707>.
- [45] Kyeremateng JDA, Edusei AK, Dogbe J, Opoku MP, Nketsia W, Hammond C, et al. Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. *Afr J Disabil*. 2019;8:577. Available from: <https://doi.org/10.4102/ajod.v8i0.577>.
- [46] Henry G, Webb A, Galea C, Pearce A, Balde I, Garrity F, et al. Out-of-pocket costs for families and people living with cerebral palsy in Australia. *PLoS One*. 2023;18(7):e0288865. Available from: <https://doi.org/10.1371/journal.pone.0288865>.
- [47] Dlamini MD, Chang Y. Caregiver burden in caring for children with cerebral palsy: A concept analysis. *International Journal of Health Medicine and Nursing Practice*. 2025;7:1-23. Available from: <https://doi.org/10.47941/ijhmn.2465>.
- [48] Houtven CHV, Voils CI, Weinberger M. An organizing framework for informal caregiver interventions: Detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatr*. 2011;11:77. Available from: <https://doi.org/10.17615/391t-ys19>.
- [49] Aswegen T van, Myezwa H, Potterton J, Stewart A. The effect of the Hambisela programme on stress levels and quality of life of primary caregivers of children with cerebral palsy: A pilot study. *S Afr J Physiother*. 2019;75(1):461. Available from: <https://doi.org/10.4102/sajp.v75i1.461>.

- [50] Marrón EM, Redolar-Ripoll D, Boixadós M, Nieto R, Guillamón N, Encuentra EH, et al. Burden on caregivers of children with cerebral palsy: Predictors and related factors. *Univ Psychol*. 2013;12(3):767-777. Available from: <https://doi.org/10.11144/javeriana.upsy12-3.bccc>.
- [51] Steffen AM, McKibbin CL, Zeiss AM, Gallagher-Thompson D, Bandura A. The Revised Scale for caregiving self-efficacy: Reliability and validity studies. *J Gerontol B Psychol Sci Soc Sci*. 2002;57(1):P74-86 Available from: <https://doi.org/10.1093/geronb/57.1.p74>.
- [52] Zeiss AM, Gallagher-Thompson D, Lovett S, Rose J, McKibbin CL. Self-Efficacy as a mediator of caregiver coping: Development and testing of an assessment model. *Journal of Clinical Geropsychology*. 1999;5:221. [cited 2025 Nov]. Available from: <https://doi.org/10.1023/a:1022955817074>.
- [53] Chaparro-Díaz L, Carreño-Moreno S, Reyes JR. Adopting the role of caregiver of chronic patients: Specific situation theory. *Aquichan*. 2022;22(4):1. Available from: <https://doi.org/10.5294/aqui.2022.22.4.2>.
- [54] Can V, Aysin N, Bulduk M, Dilbilir Y. The relationship between self-efficacy and caregiving burden among parents of children with cerebral palsy. *J Health Sci Med*. 2025;8(2):232-240. Available from: <https://doi.org/10.32322/jhsm.1597750>.
- [55] Guillamón N, Nieto R, Pousada M, Redolar D, Muñoz E, Encuentra EH, et al. Quality of life and mental health among parents of children with cerebral palsy: The influence of self-efficacy and coping strategies. *J Clin Nurs*. 2013;22(11-12):1579-90. Available from: <https://doi.org/10.1111/jocn.12124>.
- [56] Albanese AM, Russo GR, Geller PA. The role of parental self-efficacy in parent and child well-being: A systematic review of associated outcomes. *Child Care Health Dev*. 2019;45(3):333-363. Available from: <https://doi.org/10.1111/cch.12661>.
- [57] Provenzi L, Giusti L, Caglia M, Rosa E, Mascheroni E, Montirosso R. Evidence and open questions for the use of video-feedback interventions with parents of children with neurodevelopmental disabilities. *Front Psychol*. 2020;11:1374. Available from: <https://doi.org/10.3389/fpsyg.2020.01374>.
- [58] Hohlfeld A, Harty M, Engel ME. Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *Afr J Disabil*. 2018;7:437. Available from: <https://doi.org/10.4102/ajod.v7i0.437>.
- [59] Reich SM, Bickman L, Heflinger CA. Covariates of Self-Efficacy. *Journal of Emotional and Behavioral Disorders*. 2004;12(2):99. [cited 2025 Nov]. Available from: <https://doi.org/10.1177/10634266040120020401>.
- [60] Smeyne CN, Cooper J, Trott CD, Jockin AK. Trauma competent caregiving: A pilot examination of a virtual trauma-informed caregiver training for foster and kinship parents. *Child and Adolescent Social Work Journal*. 2025. [cited 2025 Oct]. Available from: <https://doi.org/10.1007/s10560-025-01039-5>.

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