

REVIEW

Brief review: Psychological health and life quality of cerebral palsy

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Abstract: Cerebral palsy is the most common cause of disability that develops in infancy. This complex disorder affects adult life in a powerful way. Challenges include performing motor skills and achieving physical capabilities. The majority of individuals also report lifelong psychosocial stressors. Furthermore, mental health issues occur more commonly in this patient subset, as do struggles with employment and education. Often the severity of challenges correlates to the severity of the cerebral palsy. The prognosis of individuals with cerebral palsy has improved over the last three decades, although it continues to be a lifelong condition. In order to promote healthy aging across their lifespan, intervention programs should be considered to improve physical well-being, and care should be taken to maintain mental health.

Keywords: cerebral palsy, anxiety, depression, disability, caregivers, quality of life

1 Introduction

Cerebral palsy (CP) is a congenital disorder of movement, muscle tone, or posture. It is the result of abnormal central nervous system white matter development and continues to be the most common cause of disability developing in infancy [1]. CP is a group of neuromuscular diseases that is primarily common in the pediatric population and is the most common cause of neurological and motor disability in children [1,2]. According to the Centers for Disease Control and Prevention, 1 in every 323 children in the United States has been identified as having cerebral palsy. Cerebral palsy is comprised of various subtypes with the most common type being spastic cerebral palsy [1,2]. Symptoms of CP include exaggerated reflexes, floppy or rigid limbs, and involuntary motions that begin to appear by early childhood [2]. How such a complex disorder affects adult life raises important questions on the critical issues of consideration, as well as the most appropriate healthcare resources worth implementing, starting in early childhood, that can best assist patients and their families.

Treatment interventions vary greatly, depending on severity of the symptoms, and can range from physical and other therapies to medications and even surgical interventions. The diagnosis may occur as a singular condition, or may present in combination with intellectual disability, seizure disorders, vision or hearing impairment, speech impairment, scoliosis, and contractures, among other conditions [3,4].

It is generally recognized that mental and physical health are deeply intertwined. The most commonly identified mental health conditions that co-occur with CP are anxiety and depression. In a recent study, nearly half of children with cerebral palsy self-reported anxiety. In 2020, a mental health study on adults with CP demonstrated increased levels of anxiety and depression. Reports of decreased quality of life are also very common and will be reviewed and discussed in this article [2,5].

2 Cerebral palsy and mental health

As previously emphasized, cerebral palsy (CP) remains as the most common cause of disability developing during infancy. Defining the complex role of this disorder in affecting mental health is critically important in combination with assessing and screening for additional medical conditions and psychosocial stressors [6,7]. In 2020, the World Health Organization (WHO) estimated that 347 million people globally suffer from depression and 284 million people report anxiety. The presence of a chronic medical conditions increases this risk of anxiety and depression; if mental health is left undiagnosed or untreated, there is greater risk of worsening of health status and poor outcomes [10]. Indeed, people with disabilities or chronic medical conditions may be 3-4 times more likely to develop depression and anxiety disorders. However,

when patients with chronic medical conditions such as CP are seen by medical professionals, physicians are more likely to forego screening for mental health symptoms or conditions [10].

Mental health issues can lead to fragmented sleep patterns, disrupted appetite, and decreased energy levels [6,7]. They may also worsen cognition and executive functioning. If untreated, patients with these conditions are more likely to make unhealthy lifestyle choices and less likely to socialize. Even in light of the increased concomitance of mental health disorders with other chronic diseases, research suggests that these poorer outcomes correspond to levels of stress, pain management, fatigue, coping skill sets, and social support, as opposed to the chronic medical conditions themselves. Assessing for mental health should thus be a key component of routine health screenings [10].

3 Mental health in children and adolescents with cerebral palsy

Children with cerebral palsy (CP) frequently exhibit mental health symptoms, in particular, those of depression. Asano et al (2021) [9] studied depressive symptoms in children with and without CP, to better investigate the associated predictors. Depressive symptoms were assessed using the Birleson Depression Self-Rating Scale for Children, with parents of the participants completing the Strengths and Difficulties Questionnaire. Severity of self-rated depressive symptoms was higher in children with CP than that in typically developing children. Indeed, decline in activities and enjoyment was identified as a contributor to this increased severity of depressive symptoms. There was also greater severity of depressive symptoms in children with CP, which was correlated with hyperactivity/inattention and peer problems. Asano et al (2021) [9] consequently suggest the crucialness of providing participatory opportunities in social activities from an early age [9].

Highly interrelated with mental health symptoms in this patient subset, young adults with CP reported significant pain and fatigue [8]. Except for those in the highest level of motor function, young adults with CP consistently reported higher levels of pain and fatigue than the age-equivalent general population. The authors therefore recommend careful monitoring of pain and fatigue in young adults with CP, especially those with low levels of gross motor function. They also advise rehabilitation professionals to consider combined treatment for both pain and fatigue [8].

Transition to adulthood is incredibly stressful when multiple changes co-occur. New challenges include change in healthcare providers, transition to post-secondary education or employment, and independent or supported living separate from families. Transition age is also a period when many patients first develop anxiety or depression. Cerebral palsy can intensify the stress of these challenges.

Young adults with CP often experience lower rates of employment and of post-secondary educational opportunities. They also tend to engage in fewer social activities and to live with family for an extended period of time. Young people with chronic medical conditions, including CP, who had the highest rates of depression were those who also reported a greater number of stressors related to family functioning, such as financial stress, parental mental health issues, and single parent households [10].

There are often discrepancies between reports from a child with CP and those of their parent. This highlights the value of a multi-informant approach to child quality of life assessment. Implications for rehabilitation and quality of life is an important health-related outcome in CP research and practice. Collecting both self-report and proxy data can help to highlight quality of life issues that are salient both to the parent and to the child or adolescent with CP. Selection of the appropriate quality of life instrument depends on the assessment purpose, with available measures varying in their focus on functionality, subjectivity, and illness-specific items. Quality of life assessment of children with CP should extend beyond functional abilities to include less obvious, but critically important, psychological and social issues [10].

4 Psychological health of parents and caregivers of children with cerebral palsy

Chronic health conditions and challenges to activities of daily living in children and infants has been shown to have adverse health effects on parents and families. Caregivers for patients with cerebral palsy (CP), for example, have increased prevalence of anxiety, depression, and stress, as well as increased rates of medical conditions. Increased financial burdens, resource requirements, time involvements, barriers to sleep, and stress are all believed to impact the health

burdens on families and caregivers [11]. Reports also show that these parents and caregivers experience feelings of grief and chronic sorrow, often leading to isolation and experiential avoidance [11].

Studies show, however, that family interventions offer some benefit in these qualities. Cognitive-behavioral therapy via Stepping Stones Triple P therapy (SSTP) and Acceptance and Commitment Therapy effectively helped develop psychological flexibility in these caregivers and improved experiential avoidance, although without benefit to depressive symptoms. A meta-analysis performed by Irwin et al (2019) [11] showed the potential value of various interventions, including empowerment programs, life skills, physiotherapy, health-education interventions, parent-to-parent support, family support workers, and training in child massage skills. Although there was no observed parental benefit between one category versus another, these psychological interventions showed an overall benefit to parental mental health. The only reported difference between specific interventions was that those which focused primarily on the child, such as SSTP, showed better outcomes specifically for the child [11].

5 Quality of life in cerebral palsy

Little is known about the specifics of psychological morbidities among individuals living with cerebral palsy (CP), but cerebral palsy has been linked to decreased quality of life.

Pagliano et al (2021) [4] reported that the more severe the CP, the more that patients reported intense challenges to mobility, autonomy, and self-care. On a positive note, there were gradual improvements in several quality-of-life aspects over the years, for example improvements in areas of academic attainment and employment. However, limitations persisted with autonomy in daily life which also acted to lower quality of life. As for the more profound psychological domain, there was evidence of suffering due to isolation and relational difficulties in most cases. Some of the subjects did not report these issues when filling out questionnaires but divulged this information in face-to-face interviews. Overall, Pagliano (2021) [4] suggested a need to avoid an exclusive focus on motor function goals, and rather to promote strategies that facilitate communication, participation, autonomy, and social relations [4].

With time, individuals living with cerebral palsy are at heightened risk for a number of chronic health conditions such as secondary comorbidities; these may develop due to or be influenced by the disability, the presence of impairment, and/or the process of aging [4].

6 Interventions and treatment modalities

There are numerous interventions and treatment modalities that are aimed at ensuring an improved quality of life for the patient with CP and their families. A comprehensive formulation and treatment plan should include the possible etiologies, diagnostic and assessment techniques, prevention methods, and possible rehabilitation interventions. However, the management of CP often co-occurs with frustration, depression, and anxiety. The main goal of treatment is thus to attain the highest possible quality of life for the family and the child [6].

Comorbidities of CP through adulthood are extensive. Adults living with CP or Spina Bifida had a higher prevalence of all psychological disorders and psychological multimorbidity (14.6% vs 5.4%), all cardiometabolic disorders and cardiometabolic multimorbidity (22.4% vs. 15.0%), and all musculoskeletal disorders and musculoskeletal multimorbidity (12.2% vs. 5.4%), as compared to adults without CP [3].

Furthermore, adults living with CP had a higher 4-year incidence of any psychological morbidity (38.8% v. 24.2%) as compared to adults without CP. Fully adjusted survival models demonstrated that adults with CP had a greater hazard for any psychological morbidity [hazard ratio (HR): 1.60; 95% CI 1.55-1.65], and all but one psychological disorder (alcohol-related disorders) [1,3].

7 Clinical pearls

- (1) In patients with chronic medical conditions, assessing for mental health should be a key component of routine health screenings, due to high prevalence and low screening;
- (2) In patients with CP, depressive symptoms should be assessed via both the patients and their families due to potential incongruence;
- (3) Best outcomes are associated with successful coping mechanisms, pain management, stress management, and social support, as well as participation in social activities from an early age;

- (4) Special attention should be given to patients transitioning to adulthood due to new and worsening challenges in education, employment, and housing;
- (5) Main goal of treatment should be to attain highest possible quality of life for both the patient and family.

8 Summary

Cerebral palsy (CP) is a congenital disorder of movement, muscle tone, or posture, due to abnormal central nervous system white matter development. CP continues to be the most common cause of disability developing in infancy [1]. Like many chronic medical conditions, CP frequently co-presents with increased prevalence of mental health disorders. Indeed, people with disabilities or chronic medical conditions may be 3-4 times more likely to develop depression and anxiety disorders, yet when being seen by physicians, they are less likely to receive mental health screening [10]. Research suggests that poorer outcomes in these groups correspond to levels of stress, pain management, fatigue, coping skill sets, and social support, rather than to the chronic medical conditions themselves. Assessing for mental health should thus be a key component of routine health screenings [10]. In addition to mental health screening, patients with CP should be provided participatory opportunities in social activities from an early age for optimal psychosocial development [9].

Transition to adolescence and adulthood introduces new challenges for this population, with obstacles in attaining post-secondary education, employment, and independent living, as well as may be the initial presenting period for psychiatric illness [8]. Assessing quality of life in this population at any age is complicated, however, and should include psychosocial issues, presence of comorbidities, and ability to perform activities of daily living [4, 10]. Still, with early intervention, CP may hold an excellent prognosis. The primary goal of treatment for both patient and family should thus be achievement of highest possible quality of life [6].

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