



Volume 1

Issue 1 *Inaugural Issue for the Online Journal of
Interprofessional Health Promotion*

Article 7

October 2019

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Recommended Citation

Keys, Magen and Lewis, Connie (2019) "An Interdisciplinary Approach for Treating Children with Cerebral Palsy," *Online Journal of Interprofessional Health Promotion*: Vol. 1 : Iss. 1 , Article 7.

Available at: <https://repository.ulm.edu/ojihp/vol1/iss1/7>

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An Interdisciplinary Approach for Treating Children with Cerebral Palsy

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Abstract

Cerebral Palsy (CP) is a neurological disorder that affects the brain and muscles, often causing motor and social delays. Children diagnosed with CP often require interdisciplinary care to promote quality of life and improved development of motor and social skills. Interdisciplinary teams made up of families, the patient, nurses and therapists allow for ongoing goal setting and communication of treatment plans. Each member of the team plays a significant role as they offer specialized services to enhance not only the patient's physical development but also the child's ability to build social relationships, promote autonomy, and encourage independence. An interdisciplinary approach allows for individualized care while taking the focus off of the child's limitations and placing it on the child's ability to adapt and reach their maximum potential.

Key Words: cerebral palsy, children, treatment, interdisciplinary

An Interdisciplinary Approach for Treating Patients with Cerebral Palsy

Introduction

Cerebral palsy (CP) is a neurological disorder that effects the brain and muscles. Children diagnosed with CP often have motor, verbal, and social delays. Because there is no cure for CP, treatment of the symptoms is often sought. Providing the best quality of life through resources and intervention from various healthcare disciplines becomes the focus (Zhang, Li, & Kjeldstrom, 2017). Treatment plans can provide a comprehensive outline of the child's abilities and allows for interdisciplinary teams to work together to provide the care needed. The purpose of this review is to overview various treatments available and to evaluate how an interdisciplinary approach can provide better individual achievement and quality of life for children diagnosed with cerebral palsy.

Literature Review

Background and Significance

It is estimated that approximately 2 million children, under the age of 17, suffer from some form of disability in the United States (U.S. disability statistics, 2017). According to the Children's Special Health Services in Louisiana, approximately 1 in 4 children have a disability or health care need (Louisiana Department of Health, n.d.). These needs can include developmental, behavioral, physical, or cognitive impairments brought on by trauma, disease, or environmental factors that lead to limitations requiring assistance with health care and medical management beyond what is considered routine (Definition of special health care needs, 2016). Assistance is provided to these children based on their level of need that can include minimal assistance to daily on-going care.

Cerebral palsy (CP) is a neurological disorder that effects the brain and muscles causing problems with movement, tone, and balance. Cerebral palsy can be congenital, meaning the brain did not develop normally in utero, or it can be acquired after birth, from trauma or damage to the brain often at or around birth. The severity of CP ranges from mild to severe. It not only causes muscular abnormalities but can cause intellectual disabilities as well and can be a diagnosis in conjuncture with other diagnoses (What is cerebral palsy? What causes it?, 2017). Due to the range of disabilities caused by CP, interventions should be tailored to the individual based on their need (Jeglinsky, Salminen, Carlberg, & Autti-Ramo, 2012). For children under 18 years of age, it is estimated that 500,000 are currently diagnosed with CP in the United States (Prevalence of cerebral palsy, 2019).

A collaboration between the patient, family, and an interdisciplinary team is ideal for formulating holistic treatment plans and goal setting for children diagnosed with CP. Interdisciplinary teams should assess the child's strengths, interests, and motivations when evaluating, setting goals, and delivering interventions needed (Novak et al., 2013). Goal setting should be realistic yet challenging to motivate all involved to work through the needed interventions and allow for maximum potential to be reached.

Discussion

Interdisciplinary Teams

Interdisciplinary teams are a vital part of the healthcare setting. The term "shared decision making (SDM)" is often used in reference to this collaboration of teams (Adams & Levy, 2017). Research suggests that knowledge from individual specialties collaborating with each other to provide multifaceted care to patients leads to positive outcomes. The interdisciplinary team members may vary depending on patient severity and can change based on

needs. Communication among the team is essential for exchanging information. This can take place via team meetings, audio or video conferencing, and/or through patient records. Patient records, whether paper or electronic, should be updated frequently and accessible among the interdisciplinary team to allow for accurate planning and decision making in regard to patient care (Kuziemy et al., 2009).

Family Support and Patient Involvement

In the past, families had a more passive role in decision making when it came to their child's focus within therapies. Healthcare providers often took the decision-making role with the main focus being on the limitations and disabilities of the patient. In recent years, treatment focus has shifted towards the child's functional abilities along with having a more collaborative approach between families and therapists (Kruijsen-Terpstra et al., 2014).

Having family support promotes hopefulness, goal setting, and life satisfaction for those diagnosed with cerebral palsy and is very important during the rehabilitation process. Active engagement within the family should be evaluated with their abilities, behaviors, and beliefs considered (Kruijsen-Terpstra et al., 2014). "Supportive behaviors included consistent attempts by parents to be advocates, treat participants normally, inclusion in family activities, provide therapy and encourage positive sibling relationships" (Freeborn & Knafl, 2013, p. 676). Having support, beginning at an early age and continuing into adulthood, encourages acceptance of their diagnosis and models self-advocacy.

It is important for the patient to be included in rehabilitation planning, as able, allowing for services to be provided in a safe and effective manner. Although it can be overwhelming, explaining and allowing children to participate in decision making as they age is encouraged to allow for autonomy and independence while building trust and decreasing anxiety (Vahdat,

Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). Involvement also allows for preferences to be voiced and consent to be obtained when the child is cognitively competent enough to be involved (Adams & Levy, 2017). While it is the responsibility of a parent to protect their child, it is also important for them to encourage the development of skills that will allow them to function as independently as possible. The ultimate goal of rehabilitation is to develop maximum levels of self-determination, control, resilience, and independence for the child (Heaslip & Hewitt-Taylor, 2014).

Physical Therapy

Early interventions with physical therapy (PT) or physiotherapy are recommended due to muscle involvement and motor deficiency that often is exhibited with the diagnosis of CP. PT activities can vary from range of motion to resistive exercises, often with emphasis on strength and balance training, along with muscle symmetry (Damiano, 2010). Goals of PT should be individualized and set to promote maximum function and muscle strength while preventing atrophy and contractures (Cerebral Palsy Treatment, 2015). For PT to be successful there must be treatment plans with optimal dosage ordered and an intended outcome (Damiano, 2010).

In a study completed by Morgan, et al, (2016), most of the children that were involved in some form of motor intervention showed improvements in development over their baseline.

Interventions involved an activity approach and were goal focused.

Occupational Therapy

Occupational therapy (OT) provides muscle activity with a fine motor focus. Treatment involves teaching use of extremities to assist in activities of daily living and independence such as feeding, bathing, and dressing. Equipment may be used as needed to promote fine motor use.

OT promotes recognizing abilities, desires, and willingness then adapts to achieve functioning at the child's maximum level (Occupational Therapy, 2019).

The approach of play through occupational therapy has been suggested as play is an everyday occurrence. Occupational therapist can be facilitators in helping families incorporate play into daily activities both for play sake and providing therapeutic intervention (Graham, Truman, & Holgate, 2015).

Speech Therapy

A child born with cerebral palsy is at a greater risk for having some form of communication deficit. Because communication skills play a role in building relationships, interacting, and learning, speech therapy (ST) can assist in finding communication options based on the child's need. ST also assists in the development of language comprehension (Speech and Language Therapy, 2019).

Communication abilities in children with cerebral palsy has been noted to affect their motor ability and social functioning as they age (Lipscombe et al., 2016). Through early identification of need and intervention of speech and language therapies, social development can be a factor in promoting a better quality of life (Konst, Matson, Goldin, & Williams, 2014).

Cerebral palsy children can have issues with oral motor function commonly referred to as oropharyngeal dysphagia (OPD). This can have a direct impact on the child maintaining adequate nutrition and hydration. ST can provide oral-motor work and feeding intervention while working to minimize complications such as aspiration, choking, and malnutrition (Weir et al., 2013).

Skilled Nursing Involvement

For cerebral palsied children who require assistance throughout the day there are options depending on their level of need and insurance coverage. Some patients may have a more severe diagnosis requiring them to remain homebound or be placed in an inpatient facility under the supervision of a skilled nurse. Others may be more stable and are able to attend day health centers or schools that would allow for socialization, therapies, and education within an inclusive environment while receiving skilled nursing care. Allowing for children with cerebral palsy to be around peers that have similar diagnosis, within a controlled, inclusive environment, can promote learning, interaction, coping skills, and adaptation. This environment also promotes mental and emotional development all while having trained interdisciplinary staff, working together, assisting with the needs of the patients. Skilled nurses in each of these environments can implement and oversee individualized care based on patient needs including promoting optimal health, medication administration, nutritional support, specialized therapies, and communication with physicians.

Socialization and Education

Socialization typically occurs naturally as children age; however, for children with disabilities this is often a challenging task (Socialization, 2018). Socialization is an important aspect of development that can get overlooked if the focus is primarily on providing treatment for the physical and motor development aspect. Children diagnosed with medical disabilities, or who have special health care needs, oftentimes experience a social handicap. That child may have minor disabilities which can hinder forming relationships, or they may have severe physical and/or mental disabilities that do not allow participation in traditional social activities. Providing positive social opportunities, based on the individual's needs, plays a factor in a child's socialization (Vaicekauskiene, 2008). By allowing children who have CP related disabilities to

have social interaction opportunities, better mental health, increased communication and interaction, and provide encouragement for meeting milestones is promoted. These interactive opportunities may be different from what is considered typical such as providing socialization through play (Graham et al., 2015). Education also plays a role in offering socialization opportunities (Naveed & Kasana, 2017).

Cerebral palsied children have varying intelligence levels, with most being average or above average levels, making education necessary. Depending on the child's need, parents may have a choice of a mainstream or regular school setting or a specialized education program. Some children may need assistance from other disciplines within the interdisciplinary team, so it is important for these to be available alongside teaching to support a positive learning environment. Objectives for disabled students may look different than their mainstream cohorts; however, allowing for the least restrictive setting based on the child's needs is important (Paleeri, 2010).

Pediatric Day Health Care

Pediatric day health care (PDHC) programs are offered in locations throughout Louisiana. This program is funded by Louisiana Medicaid and allows for children with complex medical or developmental disabilities to receive interdisciplinary services, such as skilled nursing, therapy services, respiratory care, social services, and education, throughout the day to assist in maintaining health and promoting quality of life in an effort to prevent death and/or prolong life (PDHC provider manual, 2011). PDHCs allow for individualized care based on patient need provided in a group setting. Each child received skilled nursing care and certified nursing assistance based on their physician ordered plan of care. Centers also provide all disciplines of therapy along with educational services while providing socialization

opportunities. Within this program, interdisciplinary communication and exchange is evident. Nurses and therapists work alongside one another to provide the needed care for each patient while having access to the patient's physician for needs or concerns. The interdisciplinary team also remains in contact with the families as they provide education, assist with needs, and provide progress updates.

Children diagnosed with CP may be candidates for PDHC services if the required qualifications are met set forth by Medicaid. Once admitted interdisciplinary care begins as the patients receive skilled nursing care with therapy services ordered by their physicians. Communication remains open between all disciplines involved throughout the patient's participation in the program.

Conclusion

“Children build their capacity to participate in daily life with a supportive and active environment, which requires well coordinated collaboration and shared multidisciplinary goals” (Jeglinsky et al., 2012, p. 211). Providing the best quality of life possible within the child's mean is important such as promoting skills, providing opportunities for social relationships, and building confidence. Family support is vital for children diagnosed with cerebral palsy as lack of family support can have a direct effect on the child as they age. Many children will model what they see their families do so those family members who advocate for them and try to include them and provide as many resources to them are instilling knowledge, confidence and feelings of acceptance. It is important for children to be involved in decision making as they age so they feel as though their thoughts and opinions are considered and it allows for topics such as risks and vulnerabilities to be discussed.

A study conducted by Kruijsen-Terpastra, et al, showed that although most families appreciated being involved and collaborating with their child's therapists, some expressed they felt insufficient and lacked confidence. Families reported needing time to build relationships before fully trusting the therapists. Therapist should be aware of the need for a fluid partnership with families, realizing uniqueness and differing preferences among families and also allowing for tasks and roles to be defined so progress can be achieved.

Families often need assistance with children diagnosed with cerebral palsy within the community, so it is important for them to have knowledge about and access to resources available. Healthcare professionals can provide assistance with not only the medical care of these children but also their social and functional development in order to give them opportunities for personal growth.

“It's easy to be an advocate for a child's health and education, but a parent must also actively be an advocate for their child's happiness” (Socialization, 2018, para. 29). Promoting a good quality of life and allowing for childhood experiences takes the focus off of the child's limitations and more on adapting their abilities.

Case Scenario

Pediatric day health centers in Louisiana offer interdisciplinary care to children birth to 21 years of age who have a medical diagnosis or disability that requires they have skilled nursing care throughout the day. This case scenario is based on the journey of an 18-month-old little girl. Her diagnoses included cerebral palsy and microcephaly with a history of seizures, and she was developmental delayed. The patient was underweight and had poor intake by mouth. She was nonverbal and had both gross and fine motor delays. She could sit up on her own and was just beginning to crawl using a 4-point stance. A pediatric day health center provided her with daily skilled nursing care, monitoring her neurological status, nutritional status, and assistance with activities of daily living. The patient received physical, occupational, and speech therapies twice a week. A curriculum coordinator provided weekly educational activities based on her developmental level. Slowly but surely, this little girl began to crawl, then stand, then take a few steps, then walk. She began learning simple sign language then learned to communicate through simple words. Since admission, the patient had complications, setbacks, and multiple new diagnoses. However, through consistent input from an interdisciplinary team working together for the betterment of this child, she is now 7-years-old and has a good prognosis and better quality of life. She continues to have speech delays but can formulate words well enough to communicate most needs. She walks, is completely toilet trained and requires very little assistance with activities of daily living. At this point, she is ready to transition into a school setting where she will receive a focus on education while having a skilled nurse that can provide care as needed.

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