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Challenges of Cerebral Palsy Management

Areej Alshehri
School of Engineering, University of Bridgeport
Department of Technology Management
Bridgeport, CT 06604
aalshehr@bridgeport.edu

Christian Bach
School of Engineering, University of Bridgeport
Department of Technology Management
Bridgeport, CT 06604
cbach@my.bridgeport.edu

***Abstract*—The purpose of this study is to discuss the challenges of cerebral palsy (CP) management. The paper will discuss CP treatment, patient care & support, clinical processes and patient quality of life as the major challenges of CP management. The paper looks at existing research with the aim of advancing current understanding on the goal, analysis and synthesis of CP. CP treatment; patient care & support, clinical processes and patient quality of life are the major challenges of CP disorder management. The focus of modern practitioners in CP management should combine the processes around diagnosis, treatment and patient care. There was limited time and resources to complete the study. This report presents findings that are important for medical practitioners, parents, caregivers and other stakeholders such as the government. The contents can help provide much needed insight that can lead to the improvement of CP management by providing solutions to the identified major challenges.**

Keywords—Cerebral Palsy Management; Scientific Causal Model; Treatment; Clinical Process; Patient Care; Quality of Life.

I. INTRODUCTION

The problems of CP (Cerebral Palsy) management differ from patient to patient. In some patients, the problems may be severe soon after birth while in other patients; they are not visible until early childhood [1]. There is no cure for the brain damage caused by CP and the same is not continuous or progressive [2]. However, the effects of brain damage may become more pronounced as the child grows. Therefore, the best strategy for doctors is a combination of methods that consist of clinical treatment and physical therapy [3]. Without these treatments, the permanent tightening of joints is very common [4]. Doctors can avoid such scenarios by ensuring treatment using a combination of methods from an early age. The comprehensive treatment should follow assessment & diagnosis of the disease [5]. Here, the parents, doctors and caregivers have a role to play since the daily activities in the life of a patient must include carrying, lifting, dressing, bathing, play, feeding and communication.

CP (Cerebral Palsy) is a very complex disorder that requires treatment and management from a dedicated team, which may include parents, doctors, speech therapists, occupational therapists, caregivers and other medical practitioners or specialists (eye specialist, surgeon and neurologist) [6]. These specialists may be required to manage different aspects in a child's life since the symptoms become more severe with time [7]. The severity that occurs with time can be accredited to subdural damage [8]. When a patient receives extensive care from specialists at a tender age, they may improve. Similarly, once muscles and bones become more established, it is more difficult to reduce the symptoms of the disorder; orthopedic surgery may be required [9].

Children born with CP are more likely to have some learning disabilities, which may be unrelated to their IQ [10]. Different patients are likely to manifest different degrees of intellectual ability [11]. The level of intellectual ability varies from genius to intellectual impairment [12]. Further, it is advisable to not ignore or underestimate the capabilities of CP patients; they should be given every opportunity available to learn [13].

The complexity of the disorder and the treatment efforts introduces many challenges in the management of CP. A comprehensive management program should begin after diagnosis [14]. Here, parents, doctors, speech therapists, occupational therapists, caregivers and other medical practitioners or specialists are involved in managing different aspects of the disorder [15]. Due to the complexity of the disorder and the treatment required, the management of CP has many challenges [16]. The purpose of this paper is to discuss treatment, care & support, patient's quality of life, and clinical process as the major challenges of CP management.

II. RESEARCH METHOD

Recently combining research methods, for instance [17] p. 112 became increasingly important in particular when pursuing the goal of gaining "rich theoretical insights [18] p. 613." One form for "developing new theoretical insights" [19] p. 506 is the review centric research approach in which a researcher reviews "existing theory and research" [19] p. 506, but the argument can be made that we also can include case study research findings that are based on the real world observation of practitioners and organizations e.g. [20], [18]. In the research presented here the focus is on combining the most important "previously established studies and concepts" that I have identified in the academic literature based on which I provide a synthesis that "advances our understanding" [19]p. 507". In this study I identify the most important success factors that help in the current business or organizational situation to build our goal to accomplish a competitive advantage. My research approach incorporates the "interpretive paradigm" in which a rich description of each

factor in our current organization context is established [18] p. 615.

III. TYPES OF CEREBRAL PALSY

There are three types of cerebral palsy that can be distinguished by their symptoms and management approaches. The man types of CP are Spastic, Ataxic and Athetoid cerebral palsy [21].

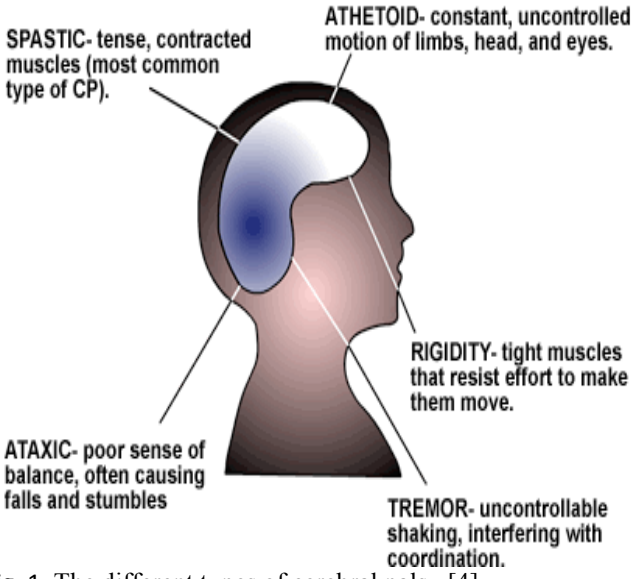

Fig. 1. The different types of cerebral palsy [4]

The cases of CP are on the rise as shown by a study conducted in the US in 2008. The figure below shows an analysis of CP cases in different locations in the US where the average of the prevalence of CP in all sites was at 3.1% of all 8 year olds in a pool of 1000 children [3].

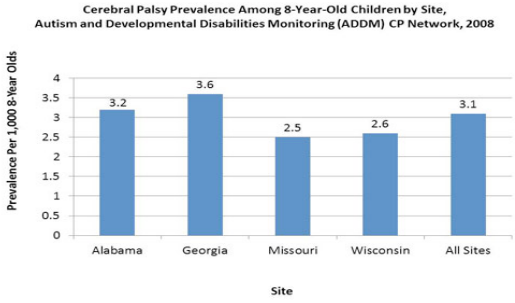

Fig. 2. The cerebral palsy rates in different sites in the US [3].

A. Spastic Cerebral Palsy

This is the most common type of CP. Spastic CP is characterized by unique muscle tightness, patients have muscle spasticity as the main impairment characteristic [22]. This type of CP occurs in at least 70% of all CP cases in the world. In cases of spastic CP, the disorder is more easily manageable as compared to other types since treatment through medication can be pursued in several neurological and orthopedic approaches. The spasticity of muscles leads to other muscle stress symptoms that may include tendinitis and arthritis in individuals who are 20-30 years old.

This type of CP can be managed using occupational & physical therapy where strengthening, stretching, exercise and other physical activities are used to manage the disorder on a daily basis. The disorder can also be managed using medications that eliminate spasticity by killing the very nerves that cause the disorder [22].

B. Ataxic Cerebral Palsy

In cases of this This type of CP is less common as compared to spasticity, it may occur in 6-10% of all cases of CP. Ataxic CP is characterized by "ataxia-type" symptoms that inflict some cerebellum damage [22].

Type of CP, the child may exhibit symptoms of unsteady posture. One may also shake while attempting to hold objects with the hand. Such symptoms are part of the motor degraded motor skills experienced by the child. One may have difficulties in their control of motor skills, which include typing, writing and holding small objects. The child may also show some disorientation and poor control while walking [22]. Visual and auditory processing may also be affected in ataxic CP.

C. Athetoid Cerebral Palsy

This is also called Dyskinetic CP; it occurs in at least 10% of all CP cases [22]. As compared to spasticity, the occurrence of this type of CP is relatively low. Patients with this type of disorder may have challenges in maintaining steady positioning. Steady sitting and walking is quite problematic; individuals may show some unintended motions.

In addition, patients may lose their ability to hold objects especially small objects that require some fine or advanced motor control. Such patients may not be able to hold small objects such as pens, coins and other small objects.

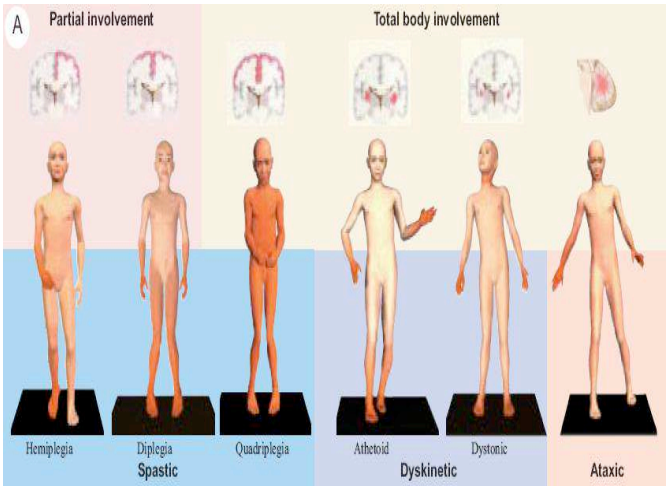

Fig. 3. The body movements in different types of cerebral palsy[23].

IV. Management of Cerebral Palsy

Cerebral palsy is not progressive in any way; there is no possibility of worsening of the brain damage. However, the symptoms may worsen with time if the patient is not given the medical care required. Medication is the first option that is sought to cure this disorder. The medication helps the patient reduce seizures, spasms and other symptoms [22]. The provision of mechanical aids also helps patients to maintain balance and other motor control needs. Accompanying treatments in emotional and psychological areas is also required to help CP patients.

After medical treatment, parents, doctors, speech therapists, occupational therapists, caregivers and other medical practitioners or specialists are involved in managing different aspects of the disorder to improve the quality life of their patients. It is important to start physical therapy soon after diagnosis and continue with this type of care throughout the life of the patient [24]. The medication given in the initial CP treatment phase may determine later complications. Injectable antispasmodics relax cramped muscles to aid motion. Other medication such as an anticholinergic reduces unwanted movements and drooling. Using anticonvulsants can reduce seizures.

However, the complex nature of this disorder leads to problems in its management. Problems such as the availability of care, medication and clinical processes come into play. Sometimes, the affordability of the treatment and care restricts the success attained in managing the disorder.

Scientific Causal Model

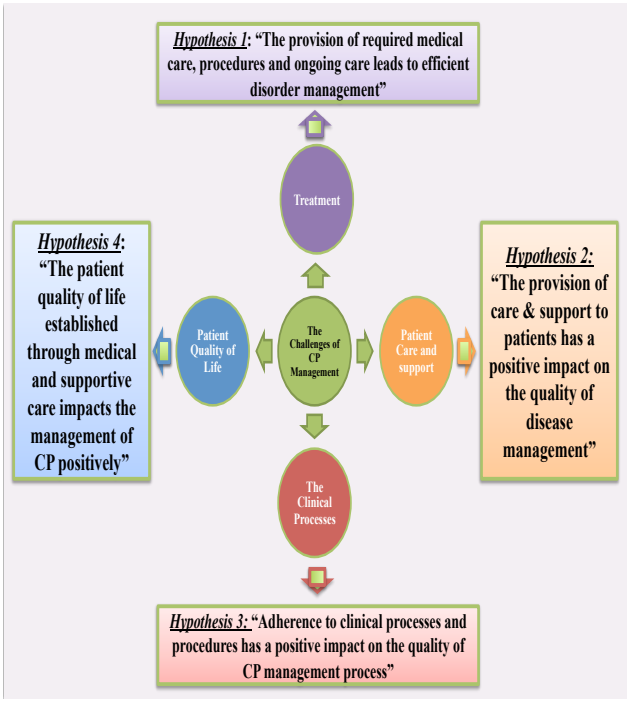

Fig. 4. The scientific causal model for the four factors of cerebral palsy management.

V. Challenges of Cerebral Palsy Management

The challenges of management of CP begin from diagnosis to the provision of care long after diagnosis. In the initial stages of the treatment process, several challenges may arise. The ability of doctors to provide a diagnosis for the disorder early in the child's life may determine the success of treatment process. The early detection and diagnosis of many disorders determines the success that can be achieved in treating such disorders [25]. Early detection and diagnosis is critical since it allows medical practitioners to begin treatment when the disorder is in its initial stages. In CP management, early diagnosis is important. Even though brain damage is not progressive, the symptoms may become severe if medication if is not provided in a timely manner [26].

The choice of treatment also has implications on the management process. The risks involved in different cases determine treatment and therapy types. In addition, the provision of specialized care by specialists such as speech therapists, occupational therapists, psychologists, language therapists, neurologists and eye specialists may also have impacts on the success of the management of CP [27]. The availability, affordability and reliability of such specialists to provide care introduce several challenges to the CP management process.

The goal of this research is to evaluate existing research to find concepts, theories and issues related to the challenges of CP management. The research will look at the challenges, risk factors, the spectrum of causal etiologies, and incidences involved in CP management [28]. The evaluation of the challenges of CP management is important to medical practitioners since it will allow such professionals to understand the issues and needs that they need to monitor in the successful management of CP [29].

In addition, the findings of this research are important to the academic community since a comprehensive analysis of the challenges of CP management will be provided to give additional concepts, findings and opinion to the already existing material in this area of study. Here, this research may also be important since it will help other researchers establish future topics of study in CP management. Further, the public can gain from this research since it adds on to the available pool of information on CP management. Parents, clinic owners, humanitarians, caregivers, and other interested stakeholders will be enlightened by the findings, prompting them to take additional interest in providing solutions to the solutions identified using resources that are at their disposal.

A. The Treatment

The diagnosis of cerebral palsy and its treatment affects the management of the disorder on a case-by-case basis. Depending on the disorder stage during the diagnosis, treatments administered and long-term management strategy, the overall management process may have different outcomes for patients. Even though the disorder is not progressive, doctors should take keen interest in ensuring that no successive brain damage occurs to the patient [30]. The overall management process should be geared towards the

avoidance of further brain damage and the provision of medication to deal with the symptoms and other additive types of care to improve the quality of patient life.

First, the availability of medication to treat the symptoms is critical in the management of CP. Doctors require antispasmodics to relax tight muscles, anticholinergic medication to manage uncontrollable body movements and anticonvulsants to treat seizures. Further, orthopedic surgery may be required for joints, muscles and tendons. Nerves in affected limbs may also be cut (selective dorsal rhizotomy) to reduce mobility problems in patients [31]. This above medication and procedures are required for the initial treatment of CP cases depending on the diagnosis. Other forms of ongoing treatment may be required to medically manage the disorder [32]. The ongoing treatments focus on adjusting existing treatment and introducing new treatments according to specialist advice. Even though brain damage in this order does not deteriorate in majority of cases, some symptoms & effects may change or deteriorate with time and age [33].

Ongoing treatment may include orthopedic surgery, dorsal rhizotomy and the provision of equipment such as casts, splints & braces to aid patients. In addition, pain management medication may be required to manage the disorder. Several issues & challenges arise from the above initial and ongoing treatments for CP [34]. First, timely diagnosis and commencement of treatment affects the success of disease management. Patients whose disorders are diagnosed and treated early may have a better chance than others who are neglected. Mistakes and misunderstandings between medical practitioners may affect diagnosis and treatment of the disorder. Secondly, the affordability and availability of medication to be used in the initial and follow-up stages of management is critical.

Patients who cannot afford or access medication have great challenges in managing the symptoms and improving their quality of life [35]. Patients located in remote areas and developing nations where availability and affordability issues are rampant may have challenges in disorder management. The availability of skilled medical practitioners to conduct specialized surgery may also be a problem. Finally, since CP patients need continued care from a combination of different people makes their cases challenging in acquiring the help of different specialists. Many regions may not have as many specialists as required to manage all CP patients.

B. Patient Care and Support

As noted above, CP patients need care from parents, doctors, speech therapists, occupational therapists, caregivers and other medical practitioners or specialists are involved in managing different aspects of the disorder [36]. After the initial treatment phase, the patients require continuous follow-up treatment and care to support them in managing the disorder. Here, parental or guardian care plays a great role since the patients require care at all times.

Patients need care to complete activities such as carrying, lifting, dressing, bathing, play, feeding and communication [37]. Such help is important to ensure that the patients improve interactions and enjoy as much a normal life as possible. In addition, patients need caregiver support for administration of medication and the use of special devices such as splints, braces & casts for improving support and motor capabilities [38]. If such specialized devices are available to patients who do not have caregivers to administer them, these powerful supportive devices may not have any impact on their lives.

When there are no caregivers for such patients, their condition may deteriorate. Financial considerations come into play when considering CP patient care and support. Since the assistance of professional caregivers may be required, families may have to shoulder the financial responsibility of acquiring necessary care for patients [30]. This is an additional cost considering the expensive medical care and specialized procedures required to manage CP. Note that regardless of the costs or efforts required to provide care to CP patients, neglect of patients may lead to the deterioration of their condition which may affect their quality of life [39].

C. The Clinical Processes

The management of CP, like any other disease management process, follows the set guidelines and processes that are supposed to establish a standard for best practices in managing the disorder [40]. The medical personnel adherence to these processes and procedures is critical in ensuring that professional assistance is given to patients. For example, the diagnosis process follows a number of processes that are supposed to culminate in a detailed diagnosis of the disorder. A sample process of diagnosis will involve the monitoring of the child development and looking for possible signs of the disorder [41].

For example, where a child is born prematurely or with a much lower weight, they should be monitored closely to watch for signs of disorders. Regular visits and examinations to look for signs should be done [42]. A sample diagnostic process may include:

1. Guardian or parent observation.
2. Clinical observation.
3. Motor skills analysis.
4. Medical history review.
5. Associative condition study.
6. Obtaining test results.
7. Diagnosis.
8. Second opinion.
9. Cause determination.
10. Assembly of a care team.
11. Development of a care plan.
12. Embracing the disorder and improving quality of life.

The above process gives an example of a guideline that is used in the diagnosis stage. While the focus of our study is not in its contents, the example shows how clinical processes can be used to improve the management of CP [43]. If such processes are not followed, the management process may be hampered greatly. It is therefore advisable that all stakeholders

follow the set guidelines to increase the overall chances of success by the patients [44].

D. The Patient's Quality of Life

The care given to CP patients helps them improve their quality of life while at the same time ensuring that the disorder does not deteriorate with time due to neglect. Caregivers have to assist patients in dressing, undressing, bathing, play, education, communication and administration of medicine & assistive devices [45].

If there are no caregivers to give such assistance to patients, their condition deteriorates even psychologically since they need interactions with other people to help cope with the disorder [46]. In addition, the quality of life of the patient is greatly improved when the concerned people give the required support to the patients [47]. Further, training such patients to improve their "self-care" abilities can help improve the quality of life since they will do some tasks on their own; reducing the need for other caregivers to assist them in all tasks.

Sometimes, when patients do not have the necessary access to medication, assistive devices, and caregiver support, their ability to learn and cope with life on a day-to-day basis is highly affected. This also affects their psychology since they may feel lonely and unwanted [48]. It is therefore critical to monitor closely the quality of the patient's life to ensure that patients are receiving the necessary help to cope with CP [49]. Devoid of this, the CP management process will be highly affected due to poor quality of life in the patients.

VI. Explanation/Discussion of Model

The scientific causal model is a framework used to evaluate the causes of phenomena or the factors that lead to a goal, here, the goal is identified as the dependent variable since it depends on the factors for its causation. The factors are also identified as the independent variables that lead to the achievement of the goal. Without the independent causative factors it is not possible for the goal to be achieved.

The scientific causal model is applied to this paper to identify the independent factors that lead to the goal. The paper begins by setting out the goal and identifying the different causative factors leading to this goal. It is beneficial to this research since it allows the researcher to begin from a central point – the goal, and end up in a model that shows the independent causative factors of this goal.

The goal of the research was to establish the challenges CP management, the paper analyses how the four factors i.e. treatment, clinical process, quality of patient life and patient care & support lead to our goal – the identification and analysis of the challenges of CP management**.**

In the analysis using the scientific causal model, the factors are the independent variables while the goal is the dependent variable that is affected by the factors. Further, the hypothesis used here is that each independent variable has a positive effect on the goal. For example, the hypothesis for analysis of factor 1 (treatment) is that "The provision of required medical care, procedures and ongoing care leads to efficient disorder management". The hypothesis for the other factors also takes similar form where a positive impact on the goal is assumed.

VII. Importance of Model/New Insight

The scientific causal model used for analysis in this research helps by providing a standard model to establish the factors that lead to a certain goal. It is important for the paper to identify the goal before finding the independent factors and formulating a hypothesis. The factors identified are the independent variables while the goal is the dependent variable. While conducting this research, the study explained the benefits of choosing a research method and scientific model to ensure that the research is guide by established boundaries.

A key lesson learnt is that there is sufficient research in most areas of study even though many of the previous works may not have focused on your specific research questions. A study can collate, summarize and conduct analysis on existing research to answer research questions. In addition, the one can contribute to the pool of existing research by conducting analysis and providing opinion based on existing research obtained from journals and books. The study experienced a change of perspective since it is believed that to answer research questions; one must conduct a primary search. In addition, the research clarifies the importance of using models; the scientific model assists to identify a goal, hypothesis and the causal factors.

The study was also informative in terms of the challenges of CP management; it is also illustrates how the lives of patients can be changed by taking a positive attitude towards the management of CP and ensuring that patients have all the necessary medical, social and moral support. The new insights gained from this study is the problems in CP management are not caused by sophisticated science problems that specialists are unable to solve, it is caused by issues that may appear trivial to most people such as poor adherence to clinical procedures and poor monitoring of patients. Therefore, since medicine to treat symptoms and equipment to carry out complex procedures is available, the focus of modern CP medical practice should be on tightening the rules around clinical processes (best practices), patient care, support, early diagnosis and the provision of affordable & accessible medical care.

VIII. Conclusion

The high complexity of the CP disorder and its treatment introduces many challenges into the management process. Doctors and caregivers are advised to begin a comprehensive management program soon after diagnosis. The guardians, parents, doctors, speech therapists, occupational therapists, caregivers and other medical practitioners or specialists collaborate in managing the disorder. However, the management process is faced by many challenges. This study has used secondary research methods to identify and discuss the major challenges of CP management.

The paper finds that the treatment, patient care & support, clinical processes, and patient quality of life are the major challenges to CP management. The scientific causal model is used to develop a hypothesis that these factors affect the goal positively. Subsequent analysis reveals that these factors affect the goal positively i.e. the four factors (that treatment, patient care & support, clinical processes and patient quality of life) are the major challenges to CP management.

Apart from insights on the application of secondary research to answer research questions through analysis, this work introduces new insights that can benefit stakeholders in CP medical practice. The findings indicate that the management of CP is not problematic because of lack of "cutting-edge" technology, medicine or sophisticated equipment to carry out procedures; rather, the challenges are caused by smaller issues whose overall effect is an ineffective management process. Therefore, the focus of current practice in CP Management should be on ironing out these "trivial looking" issues such as non-adherence to clinical processes, late diagnosis, unaffordability and unavailability of professional care for CP patients.

AUTHORS BIOGRAPHY

Areej Alshehri holds a Bachelor of Science degree in Chemistry from King Khaled University. Currently, she's a Technology Management graduate student with a concentration in Biotechnology Management at Bridgeport University. She has submitted three research papers to the Norwich conference 2013 of Norwich University and in the International Journal of Innovation and Applied Studies (IJIAS); the titles of her research are Network Marketing, Organization Research Paper, and Corporate Social Entrepreneurship and Collectivist Personal Values. Areej's research interests include Biotechnology, Entrepreneurship, Science and Biomedical engineering. Increased knowledged in Cerabal Palsy caused the author to have an increased interest in Cerabal Palsy as a topic for her thesis.

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