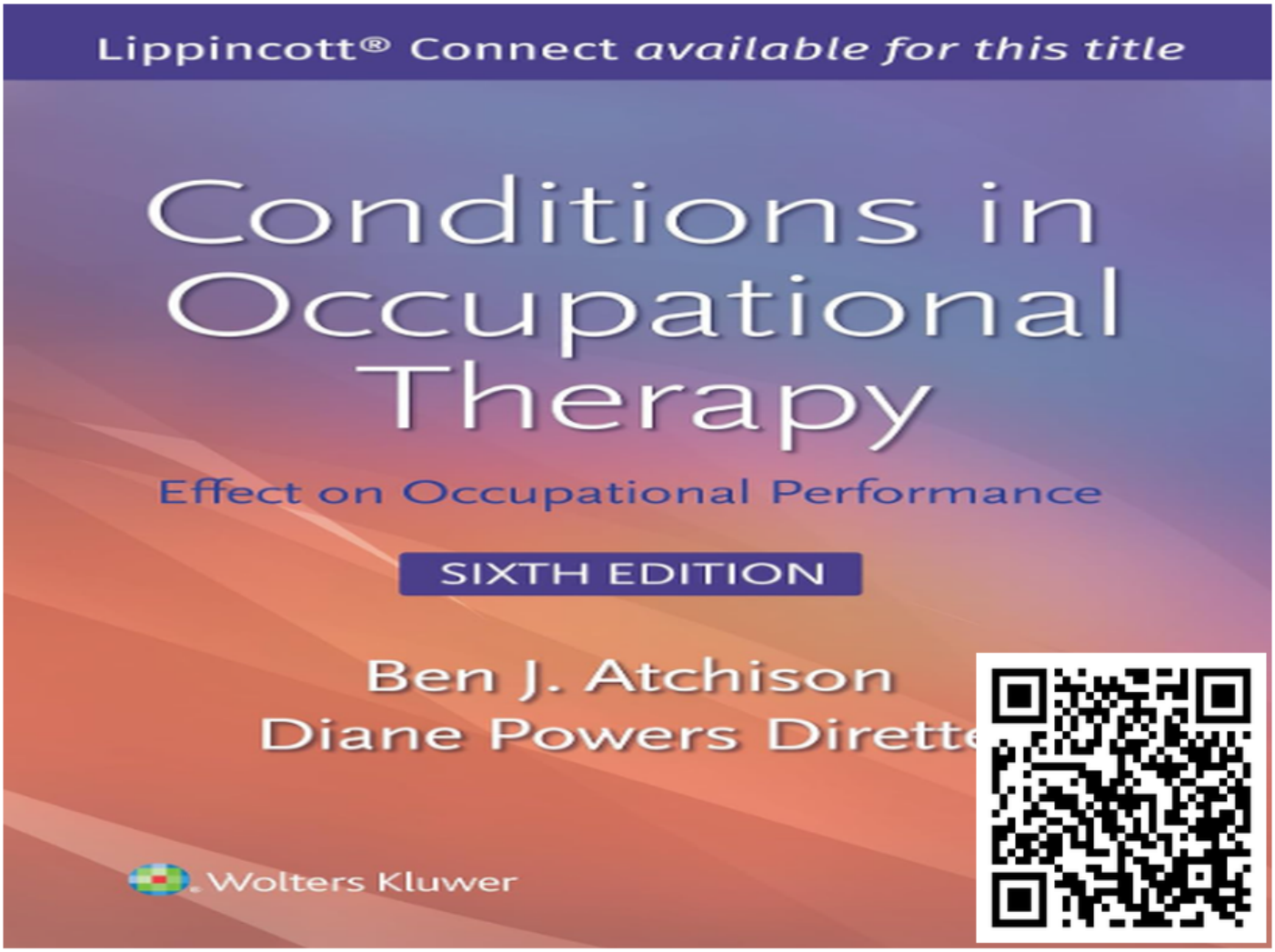

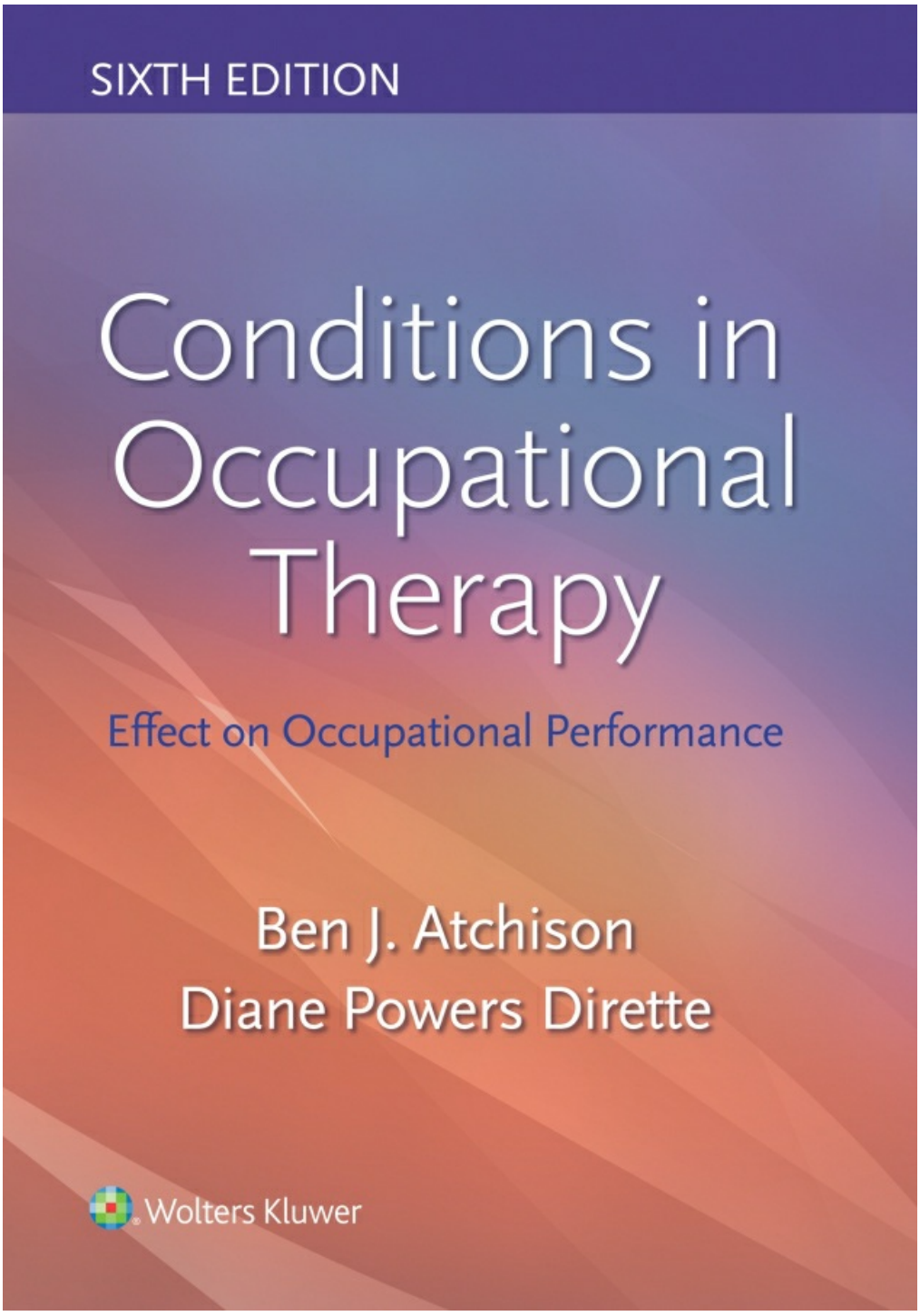
SIXTH EDITION
Conditions in Occupational Therapy
Effect on Occupational Performance
Ben J. Atchison
Diane Powers Dirette
Wolters Kluwer

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To my wife, and best friend, Marcia. I am forever grateful for all that you do.

—Ben J. Atchison

To my brother, Roddy. Thank you for always being there for my daughters and me.

—Diane Powers Dirette

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Preface

Welcome to the sixth edition of *Conditions in Occupational Therapy: Effect on Occupational Performance*. Since 1993, when the first edition was published, the purpose has remained consistent: to provide occupational therapists with epidemiological information about common conditions of the people with whom they work and to identify the impact these conditions have on their occupational performance. Each chapter provides detailed information about the etiology, incidence and prevalence, signs and symptoms, diagnosis, course and prognosis, and medical/surgical management of a condition and discusses the impact of the deficits in client factors on areas of occupational performance. The areas of occupational performance that are addressed in this new edition include activities of daily living, instrumental activities of daily living, health management, rest and sleep, education, work, play and leisure, and social participation. Each chapter also includes case illustrations to provide the reader with examples of how a person with whom they work might experience the condition.

In this new edition, we have updated the areas of occupational performance based on the *Occupational Therapy Practice Framework*, fourth edition (OTPF-4). New to OTPF-4 is the inclusion of health management as an area of occupational performance. Health management is the ability to develop and maintain health and wellness routines, organize and manage one's own medical care, maintain personal care devices, and manage medication. In addition to guidance from the OTPF-4, the World Health Organization's International Classification of Functioning (ICF) was used to guide the concepts of health conditions and their relationship to body functions and structures, activities, and participation.

We have reorganized this sixth edition of the textbook into four units: Unit 1, Pediatric Conditions; Unit 2, Mental Conditions; Unit 3, Physical Conditions; and Unit 4, General Medical Conditions. The first three units were in the fifth edition but the General Medical Conditions Unit is new to this edition. The General Medical Conditions Unit includes conditions for which occupational therapists may not get primary diagnosis referrals, but which may be common in people who are treated by occupational therapists, either because they are referred for other conditions or for treatment of the secondary effects from these conditions.

We have added new chapters that provide epidemiological information and impact on occupational performance for five additional conditions. Sickle cell anemia is a new addition in the Pediatric Conditions Unit. Musculoskeletal pain and amputations are new additions in the Physical Conditions Unit. General deconditioning and infectious diseases are new additions in the General Medical Conditions Unit.

The experts who have written the chapters in this textbook provide occupational therapists with the tools they need to formulate comprehensive evaluation and treatment plans for people with these conditions either individually or in combination. The textbook does not prescribe the steps for evaluation and treatment but rather provides all the necessary information to understand the underlying condition and how it can impact a person's ability to participate in their daily occupations. We expect that each chapter is a starting point for discussion and analysis of the condition which then will lead to the development of effective intervention planning.Each chapter contributor has included a set of multiple choice questions that are available at the thepoint.lww.com

Diane Powers Dirette
Ben J. Atchison

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1

Thinking Like an OT

Ben J. Atchison and Diane Powers Dirette

KEY TERMS

Core values
International Classification of Functioning, Disability and Health
Occupational Therapy Practice Framework
Personalized medicine
Person-first language
Philosophical assumptions

It is more important to know what kind of person has the disease than what kind of disease the person has.

—Sir William Osler (Address at Johns Hopkins University, February 1905)

Lindsey is finishing her course work in occupational therapy and is now beginning her first level II fieldwork experience. Throughout her education, she has learned the importance of evidence-based practice to guide her treatment decisions. Her challenge now is to develop her clinical reasoning skills to merge the science she has learned with the art of practice. To achieve this, she must understand the person's diagnosis, analyze the person's unique set of problems based on the person's individual characteristics and determine the impact on occupational performance. The first step of this process is the referrals she receives. Each referral gives her some basic information about the person including the person's diagnosis. Her job is to decide what to do next.

How does a student learn to correlate general information about a diagnosis with the needs of a particular person and to identify the problems that require occupational therapy intervention? How does a staff therapist set priorities for problems and decide which require immediate attention? How much problem identification can be done before the therapist actually sees the individual? How do supervisors know when their student or staff therapist is effectively screening referrals and anticipating the dysfunction that the patient might be experiencing? These first steps are essential to the actual intervention process and are the first steps on ongoing clinical reasoning.

The clinical reasoning procedure used by each health care professional is somewhat different. The main focus of intervention for a speech therapist will differ from that of a psychologist or a nurse. An essential skill of the occupational therapist is to effectively gather and apply information that leads to a plan to help people function in their daily activities. Such

data gathering and analysis provide the therapist with the foundation for a treatment plan through a prioritized list of anticipated problems or dysfunctions for an individual.

To comprehend the unique aspects of occupational therapy requires an understanding of the core values, philosophical assumptions, and domain of concern of the profession, as well as the language that is used to communicate information clearly and precisely.

Core Values of Occupational Therapy

The **core values** of occupational therapy were initially and officially published in the document "Core Values and Attitudes of Occupational Therapy Practice" (Kanny, 1993) and have been continuously reaffirmed by way of official documents published by the American Occupational Therapy Association including the Occupational Therapy Code of Ethics (AOTA, 2015) and the most recent revision of Occupational Therapy Practice Framework (4th edition) (AOTA, 2020). In addition, the Accreditation Standards for Occupational Therapy Education (ACOTE) includes the requirement that all levels of educational programs in occupational therapy ensure that students demonstrate knowledge of the AOTA Code of Ethics through application of the core values in everyday practice. There are seven core values that have been identified including altruism, dignity, equality, freedom, justice, truth, and prudence and are defined as follows:

1. Altruism is the unselfish concern for the welfare of others. This concept is reflected in actions and attitudes of commitment, caring, dedication, responsiveness, and understanding.
2. Dignity emphasizes the importance of valuing the inherent worth and uniqueness of each person. This value is demonstrated by an attitude of empathy and respect for self and others.
3. Equality requires that all individuals be perceived as having the same fundamental human rights and opportunities. This value is demonstrated by an attitude of fairness and impartiality.
4. Freedom allows the individual to exercise choice and to demonstrate independence, initiative, and self-direction.
5. Justice places value on the upholding of such moral and legal principles as fairness, equity, truthfulness, and objectivity.
6. Truth requires that we be faithful to facts and reality. Truthfulness or veracity is demonstrated by being accountable, honest, forthright, accurate, and authentic in our attitudes and actions.
7. Prudence is the ability to govern and discipline oneself through the use of reason. To be prudent is to value judiciousness, discretion, vigilance, moderation, care, and circumspection in the management of one's affairs, to temper extremes, make judgments, and respond on the basis of intelligent reflection and rational thought (Kanny, 1993).

These seven core values are the foundation of the belief system that occupational therapists use as a moral guide when making clinical decisions. A seminal article by Peloquin (2007) suggested that occupational therapists consider five additional core values to further reflect the "ethos" of our profession. She eloquently described a profession's ethos as "an interlacing of sentiment, value, and thought that capture its character, conveys its genius, and manifests its spirit." (p.

475). Simpson and Weir (1989; as cited in Peloquin) defined these five additional core values that include the following.

- Courage: “the act of dealing with anything seen as dangerous, difficult, or painful instead of withdrawing from it.”
- Imagination: “the act or power of forming mental images of that which is not actually present; it is the act of creating new images or ideas; it is resourcefulness in dealing with new or unusual experiences.”
- Resilience: “the quality of bouncing back after being stretched or challenged … the quick recovery of strength, spirit, and good humor; resilience is buoyancy.”
- Integrity: “the quality or state of being complete, unbroken, and entire; it is the quality of being whole; it is being of sound principle.”
- Mindfulness: “the state of being thoughtful and aware.”

Peloquin provides examples of how these five additional values, plus the current seven core values, are expressed in the earliest occupational therapy literature by the founders of the profession. Readers are encouraged to review her article to further understand how they collectively describe the ethos of occupational therapy.

Philosophical Assumptions

The **philosophical assumptions** of the profession guide occupational therapists in providing client-centered therapy that meets the needs of the client and society. These assumptions express our basic beliefs about the client and the context in which the client functions (Mosey, 1996). These assumptions are as follows:

- Each individual has a right to a meaningful existence: the right to live in surroundings that are safe, supportive, and comfortable, and over which he or she has some control; to make decisions for himself or herself; to be productive; to experience pleasure and joy; to love and be loved.
- Each individual is influenced by the biological and social nature of the species.
- Each individual can only be understood within the context of his or her family, friends, community, and membership in various cultural groups.
- Each individual has the need to participate in a variety of social roles and to have periodic relief from participation.
- Each individual has the right to seek his or her potential through personal choice, within the context of accepted social constraints.
- Each individual is able to reach his or her potential through purposeful interaction with the human and nonhuman environment.
- Occupational therapy is concerned with promoting functional interdependence through interactions directed toward facilitating participation in major social roles (occupational performance); and development of biological, cognitive, psychological, and social components (client factors) fundamental to such roles.
- The extent to which intervention is focused on the context, the areas of occupational performance, or the client factors depends on the needs of the particular individual at any

given time.

Personalized Medicine

The core values and philosophical assumptions of the profession of OT lead occupational therapists to a focus on **personalized medicine**. According to Burke, Trinidad, and Press (2014), "personalized medicine is best understood as a comprehensive process to determine the best health care options for a particular patient, deriving from a partnership between patient and clinician. This approach offers the opportunity to weigh personal values and preferences as well as clinical findings" (p. 196). In addition, Topol (2014) defines personalized medicine as the tailoring of medical treatments to the individual characteristics of each patient with a focus on the individual as the source of medical data and as the driver of health care.

The core values, especially dignity, equality, and freedom, are the profession's moral guide to personalized medicine. They guide us to value differences, to treat people equally despite those differences, and to allow individuals to make their own choices based on differing perspectives and preferences.

The philosophical assumptions summarize the OT profession's basic beliefs about focusing on the rights and preferences of individuals relative to their biological and social environments. In addition, the philosophical assumptions help guide occupational therapists to form a partnership with each individual to determine the focus of the intervention. Each of these concepts forms a practice in which personalized medicine is an essential element.

Whereas the primary purpose of this book is to describe the potential impact of a condition on occupational performance, the descriptions should not be considered prescriptive or exhaustive. It is necessary to understand common facts of these conditions, including etiology, basic pathogenesis, commonly observed signs and symptoms, and precautions. However, it is equally important to recognize that the effects of a condition on occupational well-being will also be dependent on contextual factors such as age, developmental stage, health status, and the physical, social, and cultural environment (Dunn, Brown, & McGuigan, 1994). Rather than viewing an individual as a diagnostic entity, as a condition, or as the sum of biological cells, the treatment must be personalized.

Language

Although many language systems and mechanisms are available, we will discuss language from two perspectives. First, is a philosophical discussion of using **person-first language**. Second is the use of the ***Occupational Therapy Practice Framework****: Domain and Process, 4th Edition* (AOTA, 2020) that presents the professional language and the occupational therapy domain of concern.

Person-First Language

In many cases, the literature and the media, both popular and professional, describe a person with a given condition as the condition—the arthritic, the C.P. kid, the schizophrenic, the alcoholic,

the burn victim, the mentally disabled. All of these terms label people as members of a large group rather than as a unique individual. The use of person-first language requires that the person be identified first and the disease used as a secondary descriptor. For example, a woman, who is a physicist, is active in her church and has arthritis; the fourth-grade boy, who is a good speller, loves baseball and has cerebral palsy. The condition does not and should not be the primary identity of any person.

Consider the following: a father is introducing his son to his coworkers. Which of the following is the best introduction?

> "Hey, everyone, this is my disabled son, John."
> "Hey, everyone, this is my son, John, who is disabled and loves soccer and video games."
> "Hey, everyone, this is my son, John. He loves soccer and video games."

Of course, the third statement is the best choice. Yet it is common when describing a person who has a disability to emphasize the disability first. The consequence is a labeling process. According to Hansen (1998), "Although such shorthand language is commonplace in clinics and medical records, it negates the individuality of the person. Each of us is a person, with a variety of traits that can be used to describe aspects of our personality, behavior, and function. To use a disease or condition as the adjective preceding the identifying noun negates the multiple dimensions that make the person a unique individual."

The Occupational Therapy Practice Framework

The official language for the profession of occupational therapy was revised in 2020 and presented in a document entitled the *Occupational Therapy Practice Framework: Domain and Process, 4th Edition* (AOTA, 2020). The Practice Framework outlines the language and constructs that describe the occupational therapy profession's domain of concern. The domain defines the area of human activity to which the occupational therapy process is applied. The process facilitates engagement in occupation to support participation in life. The specific aspects of the domain are outlined in the language of the Practice Framework.

The Framework is organized into five aspects—occupations, contexts, performance patterns, performance skills, and client factors (Table 1.1). Occupations are various kinds of life activities in which individuals, groups, or populations engage. Occupations include activities of daily living, instrumental activities of daily living, health management, rest and sleep, education, work, and play, leisure, and social participation. Contexts are a variety of interrelated conditions that are within and surrounding the person. Performance patterns are the habits, routines, roles, and rituals used by the person in the process of engaging in occupations or activities. These patterns may enhance or hinder occupational performance. Performance skills are observable elements of action that have an implicit functional purpose. These skills are separated into the categories of motor skills, process skills, and social interaction skills. Client factors are values, beliefs and spirituality, the body functions, and the body structures that reside within the person. These client factors influence the person's participation in occupations.

TABLE 1.1 Occupational Therapy Practice Domain

Occupations	Contexts	Performance Patterns	Performance Skills	Client Factors
Activities of Daily Living (ADL) Instrumental Activities of Daily Living (IADL) Health Management Rest and Sleep Education Work Play and Leisure Social Participation	Environmental Factors Personal Factors	Habits Routines Roles Rituals	Motor Skills Process Skills Social Interaction Skills	Values, Beliefs and Spirituality Body Functions Body Structures

Each of these client factors has a relationship and influence on the others. The outcome is, of course, the ability to function and engage in occupations. Although at any given time the occupational therapist may focus on an occupation or client factors, the ultimate concern is whether the individual is able to function in daily life. For example, a therapist may evaluate a person's attention span, but not in isolation. Attention span is evaluated within the realm of the performance patterns and context of the person—the attention span required to work on an assembly line, to drive a car, to learn a card game, or to conduct a business meeting.

Once a therapist knows the diagnosis and age of the person, he or she can use this Practice Framework to examine systematically the deficits that occur in the client factors, as well as how these particular deficits can and do alter the person's ability to complete functional activities relevant to occupations. In other instances, the therapist may focus primarily on the occupation or the context, without paying much attention to the underlying client factors that influence the occupational performance.

International Classification of Functioning, Disability and Health

A traditional medical model that focuses solely on the medical condition is not always sufficient for considering the true impact of the condition on a person's ability to function. **The International Classification of Functioning, Disability and Health** (ICF) was developed by the World Health Organization as a comprehensive classification of function and dysfunction related to physical and psychosocial conditions that is applicable across multiple contexts and

cultures (World Health Organization, 2001). The ICF begins with the condition and then frames the condition in terms of the impact on body functions and structures, activities, and participation with the acknowledgement that this impact is influenced by environmental and personal factors (Fig. 1.1).

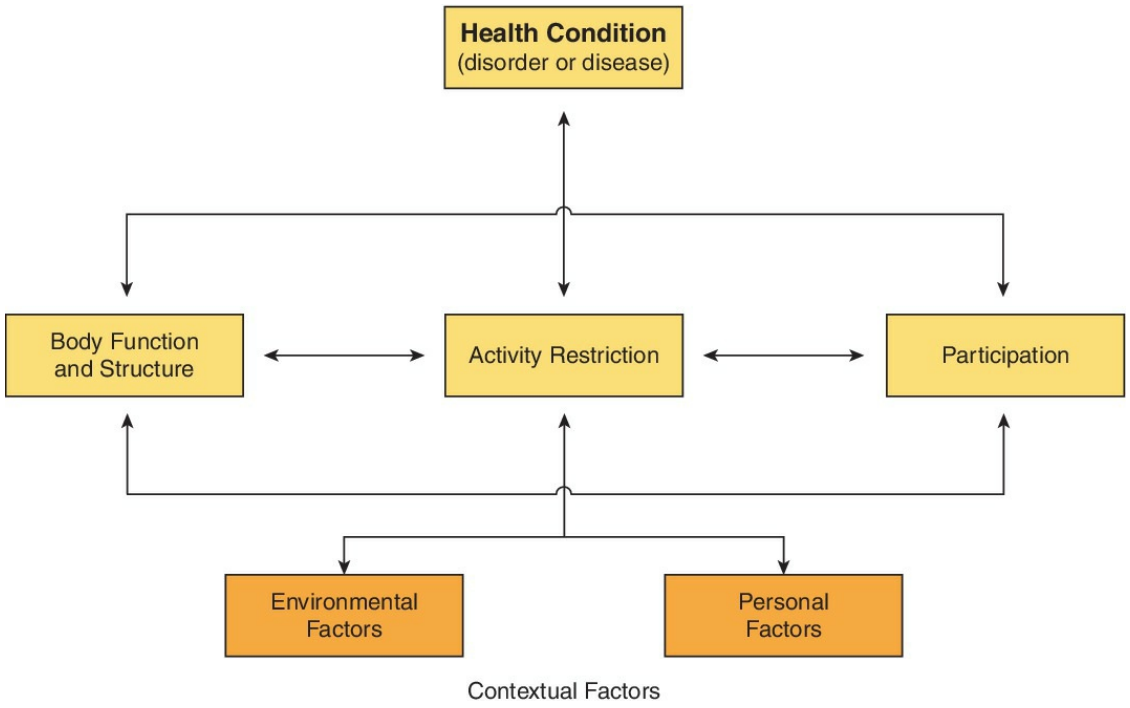

Figure 1.1 International Classification of Function, Disability and Health (ICF) model of health and disability. (Reprinted with permission from Ferkel, R. D. (2016). *Foot and ankle arthroscopy* (2nd ed.). Wolters Kluwer.)

Further, the ICF describes the interaction among these components that influence and modify one another. This model is especially useful for occupational therapists who are concerned not only with the health condition but also with the impact of the condition on occupational performance.

The ICF matches well with the framework of this textbook and is a useful tool for understanding the interaction of the components that are discussed in each chapter. As with the ICF, each chapter begins with a definition and description of the condition. The signs and symptoms outline the impact on body functions and structures and the sections describing the impact on occupational performance elucidate the impact of the condition on activities and participation. Finally, the case studies illustrate how varied environmental and personal factors interact with the other components to influence a person's ability to function.

Framework of this Textbook

As an instructional tool, this book provides an opportunity to examine each condition closely.

The reader is urged to use the information as a springboard for further study of the conditions included here and the many other conditions that occupational therapists encounter in practice. The analysis of the impact on occupational performance for a particular condition is dynamic, and the identification of the most important areas of dysfunction and, therefore, treatment will vary from therapist to therapist. In addition, factors such as secondary health problems, age, gender, family background, and culture contribute greatly to the development of a unique occupational performance profile for each individual served.

The occupational performance approach to the identification of dysfunction described in this book can be used to examine the effects of any condition on a person's daily life. This process will enable the therapist to identify and set a priority for problems in occupational performance, which, in turn, will serve as the foundation for creating an effective intervention plan.

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UNIT
1

Pediatric Conditions

The Pediatric Conditions Unit includes the most common conditions that children have who are treated by occupational therapists as determined by the National Board of Certification in Occupational Therapy. These chapters focus on conditions that are typically diagnosed in childhood, but many of them affect people throughout their life span. Each chapter provides information about the etiology, incidence and prevalence, signs and symptoms, diagnosis, course and prognosis, medical/surgical management, and impact on occupational performance of these conditions. Case illustrations are used to provide examples of lives affected by the condition. The conditions included in this unit are the following:

CHAPTER
2

Cerebral Palsy

Angie K. Boisselle

Key Terms

Ataxia
Athetosis (dyskinetic)
Contracture
Diplegia
Dysarthria
Dystonia
Extrapyramidal
Gastroesophageal reflux
Hemiplegia
Hydrocephalus
Hypertonicity (spasticity)
Hypotonicity
Nystagmus
Primitive reflexes
Quadriplegia
Scoliosis
Strabismus

A couple who had been trying to conceive a child for several years were thrilled when a family friend asked if they would be interested in adopting a baby girl that had just been born to a young unmarried woman in her church. The baby was born 6 weeks early and weighed only 4 lb, but she appeared to be healthy. After initiating the paperwork for a private adoption, they brought the baby home and named her Jill. By the time of Jill's 6 month well baby visit, her parents had become concerned. She appeared to be a bright baby who smiled and cooed and enjoyed reaching for and playing with toys, but her legs seemed stiff and she was not yet rolling over. They spoke with their family doctor about their concerns but he assured them that Jill was developing normally, and they had nothing to be concerned about. By the time of Jill's 9-month well baby visit, her parents' concerns were only growing. Jill was still not sitting up and had not yet learned to roll over or crawl. Her doctor decided to refer Jill to the county early intervention program for a developmental assessment. Jill was assessed by the early intervention team consisting of an occupational therapist, physical therapist, and speech and language pathologist. The occupational therapist noted some mildly increased tone and incoordination in her upper extremities and a 2- to 3-month delay in fine motor and self-help skills. The physical therapist

noted that Jill had hypertonicity and retained primitive reflexes in her lower extremities, which was causing significant delay in the acquisition of gross motor skills. The speech and language therapist found Jill's cognitive, language, and social skills to be at age level. The team suggested to the parents that they have a pediatric neurologist assess Jill, as she was demonstrating some of the signs and symptoms of cerebral palsy. Both the occupational and physical therapist recommended that therapy services begin as soon as possible. An Individualized Family Service Plan (IFSP) was developed at a subsequent meeting, and Jill began receiving weekly physical and occupational therapy services.

Jill's parents took her to a pediatric neurologist who conduct a neurological assessment and cranial MRI. She was diagnosed with spastic diplegia, a type of cerebral palsy. Her parents were initially overwhelmed and devastated by the diagnosis. The next year was very difficult as they grieved the loss of so many dreams that they had for Jill and faced so much uncertainty about her future. They waded through an array of possible therapy approaches and medical and surgical interventions that were recommended trying to decide which would be right for Jill and their family. They struggled to find time to work on home exercises that had been prescribed for Jill. The strain became so great that they even separated for a period but eventually reconciled. By the time Jill turned 3 years old, she was walking with a walker and able to sit in a chair independently, although she needed some assistance with changing positions. She was feeding herself but not yet dressing herself. They enrolled her in a preschool special education classroom where she received therapy services. By kindergarten, Jill was in a regular education classroom with a paraeducator for safety and support. Jill was a happy child, who had many friends and did well academically. Jill most likely will continue to need some type of additional support in order to be an independent adult, but all involved were optimistic about her future.

Description and Definition

Cerebral palsy is a complex, heterogeneous condition that primarily impacts motor function. It can occur at different times during development: congenital cerebral palsy occurs before or during birth, and acquired cerebral palsy occurs after birth. The international consensus definition of cerebral palsy has been prominent over the past decade.

Cerebral palsy is a brain-based, nonprogressive, permanent condition that has a prenatal or perinatal origin. The most prominent features include motor impairment with accompanying disorders of sensory function, cognition, speech, and in some cases, seizures (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007).

Overall, the injury or insult occurs when the brain is still developing. It can occur anytime during the prenatal, perinatal, or postnatal periods. There is some disagreement about the upper age limit for a diagnosis of cerebral palsy during the postnatal period. An upper age limit ranging from 2 to 8 years of age is applied to postneonatally acquired brain injury. Cerebral palsy is not progressive. Once the initial insult to the brain has occurred, there is no further worsening of the child's condition or further damage to the central nervous system. However, secondary conditions and activity limitation may contribute to further functional impairment throughout the life span (Bosanquet, Copeland, Ware, & Boyd, 2013).

Cerebral palsy always involves a disorder in sensorimotor development that is manifested by abnormal muscle tone and stereotypical patterns of movement. The severity of the impairment

ranges from mild to severe. The sensorimotor disorder originates specifically in the brain. The muscles themselves and the nerves connecting them with the spinal cord are normal. Although some cardiac or orthopedic problems can result in similar postural and movement abnormalities, they are not classified as cerebral palsy. Some premature babies demonstrate temporary posture and movement abnormalities that look similar to patterns seen in cerebral palsy but resolve typically by 1 year of age. For children with cerebral palsy, these difficulties persist, and it is often a lifelong disability.

Classification of Cerebral Palsy

The manner in which cerebral palsy has been classified has changed over the years. Currently, it is commonly described by several different factors, including the areas of insult within the brain, motor typology related to anatomical location, and functional status. Motor typography is described in the following sections according to neurological locations (Fig. 2.1): pyramidal and extrapyramidal.

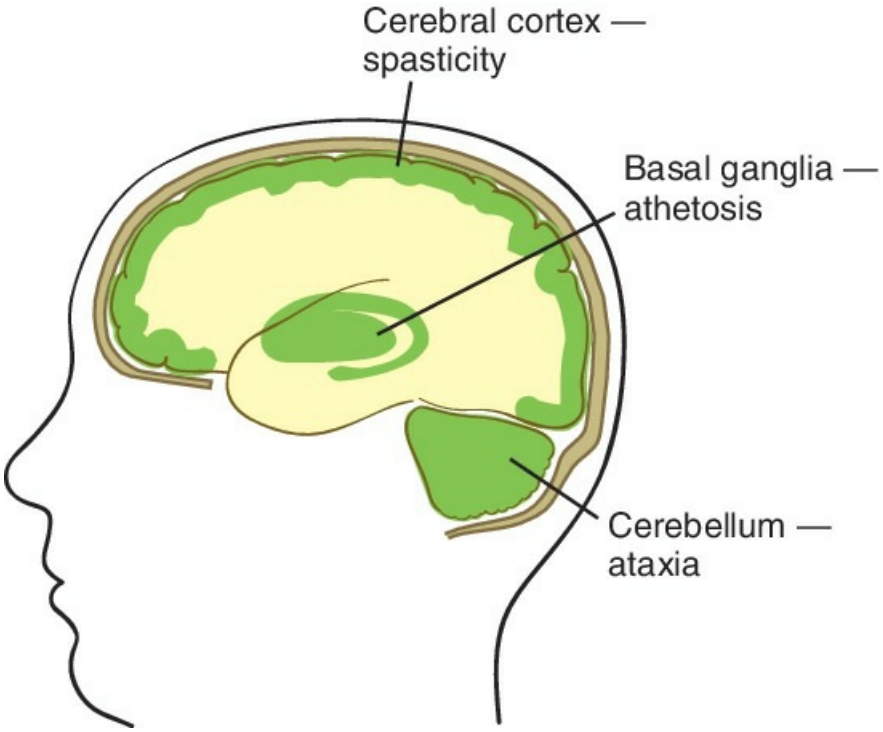

Figure 2.1 Cerebral palsy. Shown are the major parts of the brain involved in each of the three major types of cerebral palsy: spastic, athetoid, and ataxic. (Reprinted with permission from Wilkins, E. M., & Wyche, C. J. (2013). *Clinical practice of the dental hygienist* (11th ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.)

Pyramidal

Pyramidal cerebral palsy involves the occurrence of spasticity and arises within the pyramidal

tracts of the brain, which includes the corticospinal tract that ends in the spinal cord and the corticobulbar tract that ends in the brain stem.

Spasticity is a type of **hypertonicity** that is velocity dependent, meaning the muscles are more resistive to sudden, passive movement. Deep tendon reflexes are present in affected limbs and motor control is affected by the hypertonicity. This type is the most common and accounts for ~80% of cases of cerebral palsy (CDC, 2020). The impact on motor function can range from a mild impairment that does not interfere with functional skills, such as not having isolated finger movement, to a severe impairment, where there is an inability to reach and grasp. **Contractures**, which result in permanent shortening of a muscle or joint and deformities, are common (Fig. 2.2). Spastic cerebral palsy is categorized anatomically according to the area of the body that is affected. Often each area is distinguished by either weakness (–paresis) or paralysis (–plegia). Spastic hemiplegia, spastic diplegia, and spastic quadriplegia are the most common types and described below. More nontraditional types include triplegia, which involves both lower extremities and one upper extremity, and double hemiplegia, which asymmetrically involves all limbs (Glader & Stevenson, 2019).

Figure 2.2 Due to spasticity and limited controlled movement and range of motion in upper extremities and hands, this person is using a mouth stick to activate a computer. Note wrist flexion contracture. (Reprinted with permission from Carter, P. J. (2011). *Lippincott's textbook for nursing assistants: A humanistic approach to caregiving*. (3rd ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.)

Spastic Hemiplegia

Spastic **hemiplegia** involves one entire side of the body, including the head, neck, and trunk. Usually, the upper extremity is most affected. Early signs include asymmetrical hand use during the first year or dragging one side of the body when crawling or walking. The child learns to walk later than is typical and when walking the child typically hyperextends the knee, and the ankle is in equinovarus or equinovalgus position on the involved side. The child often lacks

righting and equilibrium reactions on the involved side and will avoid bearing weight on this side. The shoulder is held in adduction (internal rotation); the elbow is flexed; the forearm is pronated; the wrist is flexed and ulnar deviated; thumb is adducted; and the fingers are flexed (Fig. 2.3). Spasticity increases during physical activities and emotional excitement. Arm and hand use is limited on the involved side, depending on the severity. The child may use more primitive patterns of grasping and lacks precise and coordinated movement. In more severe cases, the child may totally neglect the involved side or use it only as an assist during bilateral activities.

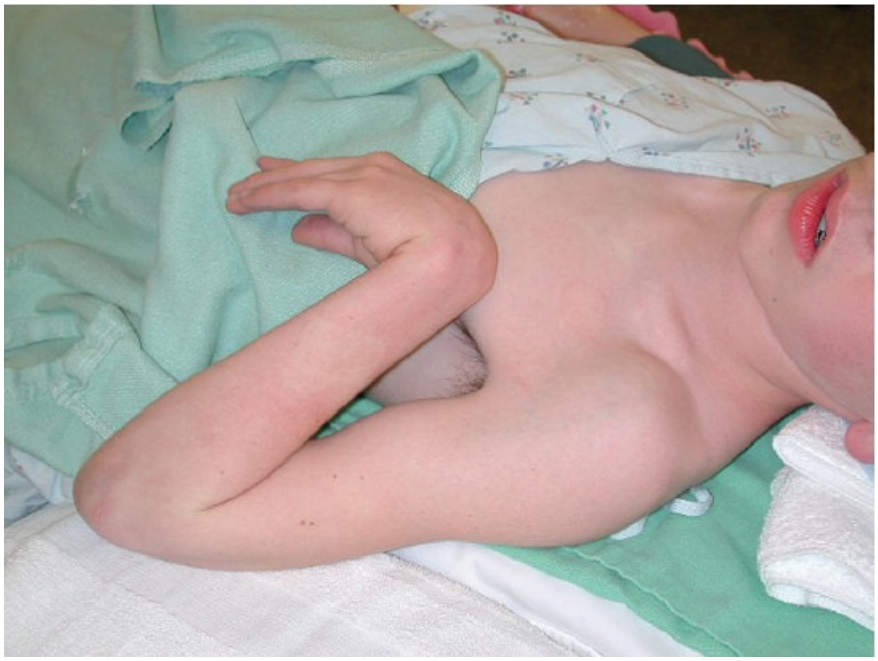

Figure 2.3 Abnormal upper extremity position due to spasticity. Note thumb adduction and flexion in the wrist and elbow. (Courtesy of Ghazi Rayan, MD.)

Spastic Diplegia

Spastic **diplegia** involves both lower extremities, with mild incoordination, tremors, or less severe spasticity in the upper extremities. It is most often attributed to premature birth and low birth weight and is, therefore, on the rise as more infants born prematurely survive as a result of medical advances. The ability to sit independently can be delayed up to 3 years of age or older because of inadequate hip flexion and extensor and adductor hypertonicity in the legs (Bobath, 1980). Frequently the child will rely on the arms for support. The young child will move forward on the floor by pulling along with flexed arms while the legs are stiffly extended. Getting up to a creeping position is difficult because of spasticity in the lower extremities. Similarly, standing posture and gait are affected to varying degrees, depending on severity. Because of a lack of lower extremity equilibrium reactions, excessive trunk and upper extremity compensatory movements are used when walking. Lumbar lordosis, hip flexion and internal rotation (scissoring), plantar flexion of the ankles, and difficulty shifting weight when walking are common (Fig. 2.4). Many of these problems result in contractures and deformities, including

dorsal spine kyphosis, lumbar spine lordosis, hip subluxation or dislocation, flexor deformities of hips and knees, and equinovarus or equinovalgus deformity of the feet (Bobath, 1980).

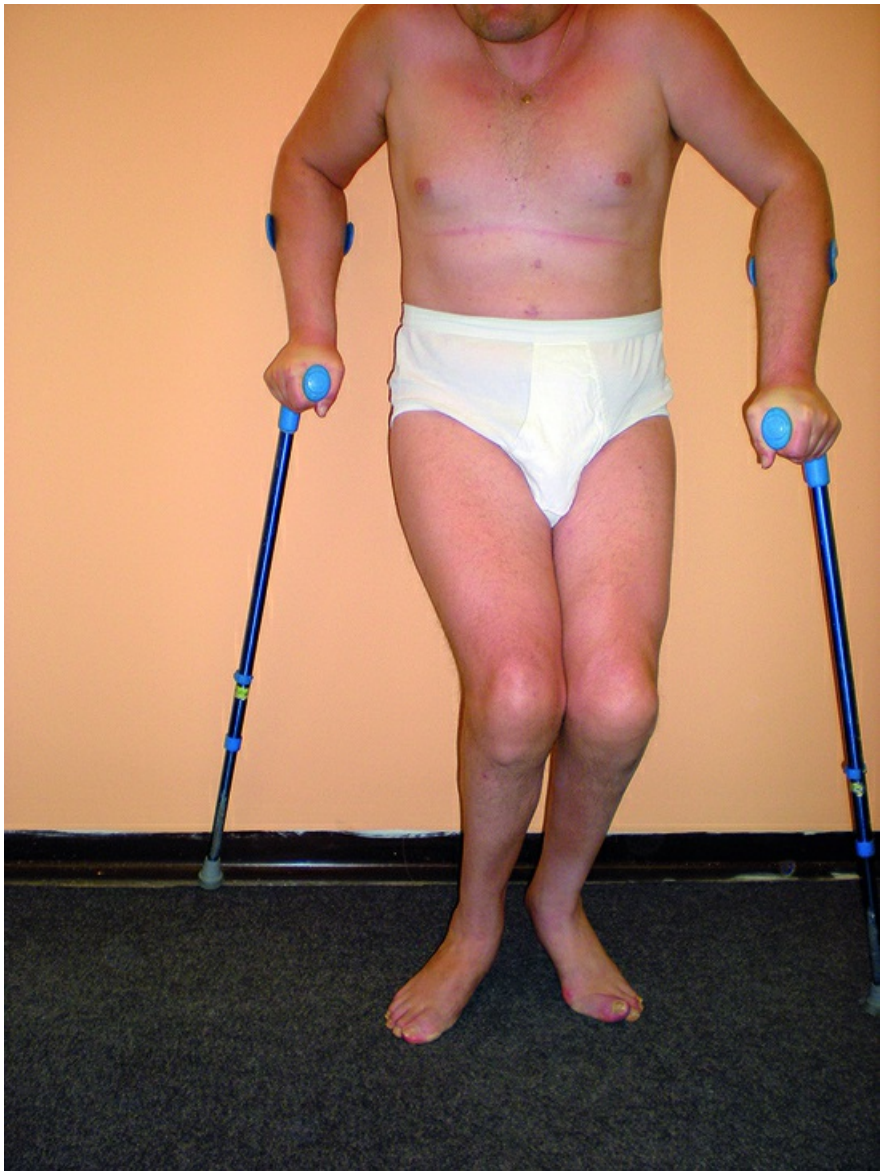

Figure 2.4 Postural effects from cerebral palsy (spastic diplegia). Note crouched posture due to abnormal muscle tone and strength: hip flexion and internal rotation; knee flexion; and equinovalgus positioning of feet. (Reprinted with permission from Liebenson, C. (2014). *Functional training handbook*. Wolters Kluwer.)

Spastic Quadriplegia

Spastic **quadriplegia** impacts all limbs symmetrically. Children with spastic quadriplegia are more likely to experience higher associated conditions and have cognitive impairment, and are less likely to ambulate. The arms typically demonstrate spasticity in the flexor muscles, with

spasticity in the extensor muscles in the lower extremities. Because of the influence of the tonic labyrinthine reflex (TLR), shoulder retraction and neck hyperextension are common, particularly in the supine position. This results in difficulty with transitional movements such as rolling or coming up to sitting. In the prone position, there is increased flexor tone, also a result of TLR influence, causing difficulty with head raising and bearing weight on the arms. Independent sitting and standing are difficult for the child because of hypertonicity, the presence of primitive reflex involvement, and a lack of righting and equilibrium reactions. Individuals are susceptible to contractures and deformities, particularly hip dislocation and scoliosis, and must be closely monitored (Fig. 2.5).

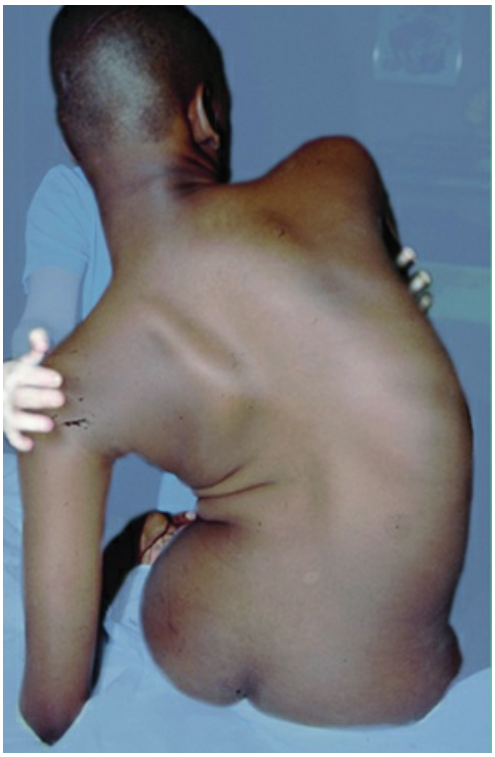

Figure 2.5 Severe scoliosis with pelvic obliquity in person with spastic quadriplegia. Scoliosis with this severity can compromise respiratory function. (Reprinted with permission from Flynn, J. M., & Wiesel, S. W. (2010). *Operative techniques in pediatric orthopaedics*. Wolters Kluwer Health/Lippincott Williams & Wilkins.)

Extrapyramidal

The **extrapyramidal** system is that aspect of the central nervous system that allows for modulation of muscle tone, posture, and movement. Extrapyramidal cerebral palsy occurs outside of the pyramidal tracts of the brain and involves a fundamental movement disorder including dyskinetic and ataxia.

Dyskinetic

Dyskinetic type is characterized by involuntary and uncontrolled movements. These movements

are typically slow and writhing. It is noted to be the most common type of **dystonia**, with an incidence of 4%-17% (Fehlings et al., 2018). **Athetosis** is the most common type of dyskinesia, characterized by slow, writhing, involuntary movements of the face and extremities or the proximal parts of the limbs and trunk. Abrupt, jerky, distal movements (choreiform) may also appear. The movements increase with emotional tension and are not present during sleep. Head and trunk control is often affected, as is the oral musculature, resulting in drooling, dysarthria, and eating difficulties.

Ataxia

Ataxia is characterized by unsteadiness and difficulties with balance, particularly when ambulating. It is the least common type of cerebral palsy and results from involvement of the cerebellum or its pathways. It is common for there to be mixed forms where two of the types occur together as a result of diffuse brain damage. The most common is spastic with athetoid. Persons with this type have signs of athetosis, and postural tone that fluctuates from hypertonicity to hypotonia. Athetoid combined with ataxia is less common. Ataxia is characterized by a wide-based, staggering, and unsteady gait. Children with ataxia often walk quickly to compensate for their lack of stability and control. Controlled movements are clumsy. Intention tremors may be present. The ability to perform refined movements such as handwriting is affected. **Hypotonicity** is often present (Glader & Stevenson, 2019).

Mixed Types

It is common for there to be mixed forms, in which two of the types occur together as a result of diffuse brain damage. Dystonia with spasticity is the most common coexisting type. Dystonia is thought to originate in the basal ganglia. It is suspected that the impact of dystonia is significantly underdiagnosed because it is fluctuating and may be difficult to identify (Fehlings et al., 2018). The American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) provides a care pathway titled Dystonia in Cerebral Palsy, which offers evidence and guidelines for clinicians (American Academy of Cerebral Palsy and Developmental Medicine, 2017).

Functional Classification

Clinicians who specialize in care of those with cerebral palsy commonly use classification systems to understand current level of motor function and limitation of children and youth with cerebral palsy. The Gross Motor Functional Classification System (GMFCS) classifies gross motor abilities and functional limitations for infants to 12 years of age with cerebral palsy. It consists of five levels ranging from level I, which includes walking without limitation, to level V, which requires transportation in a wheelchair. Each level is related to current performance with ambulation and movement within a variety of physical environments such as home, school, and community (Palisano et al., 1997). The extended, revised version (GMFCS-E & R; Fig. 2.6) was later developed to expand focus through 18 years of age (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). Similarly, the Manual Abilities Classification System (MACS) categorizes how children from ages 4 to 18 manipulate objects during activities of daily living (ADLs). Level I signifies very few limitations in hand-related activities. Conversely, level V signifies very restricted use of hands for activity (Eliasson et al., 2006). Classification systems such as the GMFCS and MACS are widely used in cerebral palsy research and practice to classify typical

performance of motor abilities across home, school, and community.

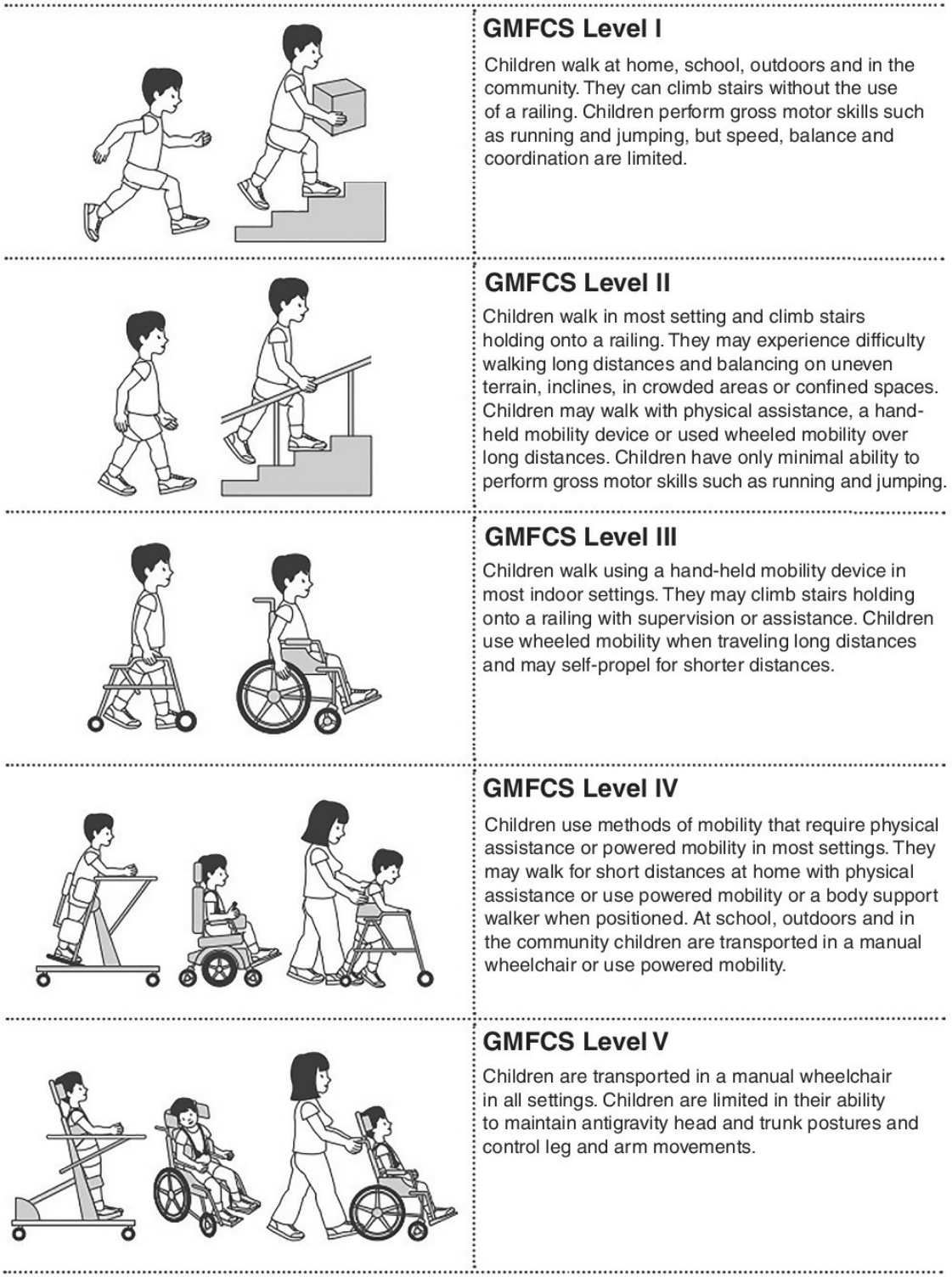

Figure 2.6 Gross Motor Function Classification System, Expanded and Revised.

(From Palisano, R., Rosenbaum, P., Bartlett, D., Galuppi, B. E., & Russell, D. J. *Gross Motor Function Classification System—Expanded & Revised*. CanChild Centre for Childhood Disability Research. Retrieved from https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r, on September 20, 2018. Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children's Hospital Melbourne ERC151050.)

Etiology

Cerebral palsy is not considered an etiological disease but is classified as a phenomenological diagnosis since understanding the signs and symptoms is key to the diagnosis and treatment (Glader & Stevenson, 2019). It is characterized as a developmental disability. Historically, birth asphyxia was considered the major cause of cerebral palsy. Dr. John William Little was known to be the first to identify cerebral palsy in 1860. He suggested that a major cause was a lack of oxygen during the birth process (Little, 1862). In 1897, Sigmund Freud disagreed, suggesting that the disorder might have roots earlier in life. Freud wrote, "Difficult birth, in certain cases, is merely a symptom of deeper effects that influence the development of the fetus" (Freud, 1968). In his monograph entitled "Infantile Cerebral Paralysis," Freud points out that a well-known painting by Spanish painter Jusepe Ribera (1588–1656), which depicts a child with infantile hemiplegia, proves that cerebral paralysis existed long before medical investigators began paying attention to it in the mid-1800s (Freud, 1968). Freud's work as a neurologist is not generally well known and, at the time that his monograph was published in 1897, he was already deep into his work in the area of psychotherapy. However, he was recognized at the time as the prominent authority on the paralyses of children. Today, cerebral paralysis is known as cerebral palsy.

Although Freud made these observations in the late 1800s, it was not until the 1980s that research supported his views (Freeman & Nelson, 1988; Illingsworth, 1985). Only a small percentage of cases of cerebral palsy are a result of birth complications. The Centers for Disease Control and Prevention (CDC, 2020) reports that 85%-90% of cases of those diagnosed with cerebral palsy have congenital cerebral palsy—that is, the injury to the brain occurred in utero. Genome studies indicate that genetic factors contribute to anywhere from 14% to 49% of CP cases. The study of genetic links within CP remains in infancy. It is anticipated that further exploration in this area will result in a more significant genetic link and expand upon the phenotypic definition of the diagnosis of cerebral palsy (Novak et al., 2017; Pham et al., 2020; Stavsky et al., 2017).

There is a large number of risk factors that can result in cerebral palsy, and the interplay between these factors is often complex, making it difficult to identify the specific cause. The presence of risk factors does not always result in a subsequent diagnosis of cerebral palsy. The presence of one risk factor may not result in cerebral palsy unless it is present to an overwhelming degree. Current thought is that often two or more risk factors may interact in such a way as to overwhelm natural defenses, resulting in damage to the developing brain. The strongest risk factors are prematurity of <28 weeks and low birth weight (Oskoui, Coutinho, Dykeman, Jetté, & Pringsheim, 2013). This is largely because premature and low-birth-weight infants are at greater risk for developing complications, especially in the circulatory and pulmonary systems. These complications can lead to brain hypoxia and result in cerebral palsy.

Additional risk factors include intrauterine exposure to infection and disorders of coagulation (National Institute of Neurological Disorders and Stroke, 2020). Maternal infection during the

perinatal period is a critical risk factor for cerebral palsy and includes infections such as maternal urinary tract infections (UTI), toxoplasmosis, cytomegalovirus (CMV), and herpes simplex virus (HSV) (Glader & Stevenson, 2019). The infection does not necessarily produce signs of illness in the mother, which can make it difficult to detect. Table 2.1 lists specific risk factors related to both congenital and acquired types of cerebral palsy.

TABLE 2.1 Cerebral Palsy: Contributing Risk Factors and Causes

Parental Influence and Developmental Periods and Events	Risk Factor/Cause
Preconception (parental background)	Biological aging (parent or parents older than 35)
	Multiple gestations
	Biological immaturity (very young parent or parents)
	Environmental toxins
	Genetic background and genetic disorders
	Malnutrition
	Metabolic disorders
	Radiation damage
First trimester of pregnancy	Endocrine: thyroid function, progesterone insufficiency
	Nutrition: malnutrition, vitamin deficiencies, amino acid tolerance
	Toxins: alcohol, drugs, poisons, smoking
	Maternal disease: thyrotoxicosis, genetic disorders
Second trimester of pregnancy	Infection: cytomegalovirus, rubella, toxoplasmosis, HIV, syphilis, chicken pox, subclinical uterine infections
	Placental pathology: vascular occlusion, fetal malnutrition, chronic hypoxia, growth factor deficiencies
Third trimester of pregnancy	Prematurity and low birth weight
	Blood factors: Rh incompatibility, jaundice
	Cytokines: neurological tissue destruction
	Inflammation
	Hypoxia: placental insufficiency, perinatal hypoxia
	Infection: listeria, meningitis, streptococcus group B, septicemia, chorioamnionitis
Intrapartum events	Uterine rupture
	Acute maternal hypotension
	Prolapsed umbilical cord
	Ruptured vasa previa
	Tightened true knot of the umbilical cord

Parental Influence and Developmental Periods and Events	Risk Factor/Cause
Perinatal period and infancy	Endocrine: hypoglycemia, hypothyroidism
	Hypoxia: perinatal hypoxia, respiratory distress syndrome
	Infection: meningitis, encephalitis
	Multiple births: death of a twin or triplet
	Stroke: hemorrhagic or embolic stroke
	Trauma: abuse, accidents

Data from UCP Research and Educational Foundation. Factsheet: Cerebral Palsy: Contributing Factors and Causes. September, 1995; Bosanquet, M., Copeland, L., Ware, R., & Boyd, R. (2013). A systematic review of tests to predict cerebral palsy in young children. *Developmental Medicine and Child Neurology*, *55*(5), 418–426. doi:10.1111/dmcn.12140; Glader, L. J., Stevenson, R. D., eds. (2019). *Children and youth with complex cerebral palsy: care and management*. Mac Keith Press; and Stavsky, M., Mor, O., Mastrolia, S. A., Greenbaum, S., Than, N. G., & Erez, O. (2017). Cerebral palsy-trends in epidemiology and recent development in prenatal mechanisms of disease, treatment, and prevention. *Frontiers in Pediatrics*, *5*(21), 1–10. doi:10.3389/fped.2017.00021.

There are four types of injuries to the brain that often result in cerebral palsy (National Institute of Neurological Disorders and Stroke, 2020):

- Periventricular leukomalacia (PVL) involves damage to the white matter in the brain adjacent to the lateral ventricles due to ischemia, or restriction in blood supply to the brain tissue. Necrosis occurs, resulting in empty areas or cysts that fill up with fluid. This is most often associated with premature birth before 32 weeks' gestation and decreased birth weight. Shang et al. (2015) conducted a study of 408 children diagnosed with CP and PVL and found that 95% of cases that involved high risk factors such as infection and hypoxia resulted in quadriplegia (CP affecting all four limbs), and the most associated disorders included visual and hearing impairments.
- Hypoxic–ischemic encephalopathy (HIE), commonly known as perinatal asphyxia, occurs when there is a loss of oxygen resulting in damage to brain tissue. It most often occurs in the full-term infant in the perinatal period and can be caused by many factors related to birth and delivery as well as fetal stroke.
- Intraventricular hemorrhage (IVH) involves bleeding into the brain's ventricular system. This most often occurs in infants born more than 10 weeks prematurely due to the blood vessels in the brain not being fully developed at this gestational period. It is rarely present at birth but develops during the first several days of life. There are four types or grades of IVH based on the amount of bleeding that occurs. Grades 1 and 2 involve a smaller amount of bleeding and typically do not result in any long-term developmental problems. Grades 3 and 4 involve more severe bleeding. **Hydrocephalus**, defined as abnormal fluid build-up in the brain, can occur when blood presses on or leaks into the brain tissue resulting in blood clots blocking the flow of cerebral spinal fluid. Grades 3 and 4 bleeds are most often associated with cerebral palsy.

Congenital malformations can occur when the brain does not grow properly or fully develop. They differ from the other three causes of cerebral palsy that are due to lesions or brain injuries. With cerebral dysgenesis, the brain did not grow properly or fully develop. The first 21 weeks of gestation are most critical for brain development, and factors such as maternal infections or trauma can result in a brain malformation. The most common type of brain malformation associated with CP is microencephaly, in which the brain does not grow (Stavsky et al., 2017). The severity of brain malformations can vary greatly with a more severe type resulting in cerebral palsy.

Acquired CP occurs more than 28 days after birth and represents a small percentage of cases. This category includes infection, cerebrovascular accidents (CVA), and injury from external causes such as motor vehicle accidents, and child abuse (CDC, 2020). A closed-head injury that occurs during this period is now classified as traumatic brain injury, even though the resulting impairments are very similar to cerebral palsy.

Incidence and Prevalence

Cerebral palsy is the most common cause of motor limitations and childhood disability globally (McGuire, Tian, Yeargin-Allsopp, Dowling, & Christensen, 2019). It is estimated that the global prevalence is 1 in 500 live births with 17 million from birth to 90 years of age (Gross et al., 2020; National Institute of Neurological Disorders and Stroke, 2020; Novak et al., 2017). Cerebral palsy is more common among males than among females at a ratio of 1:4. Romeo et al. (2016) conducted a critical review on sex differences of the various motor impairment of cerebral palsy and found more male representation of impairment across all types and severity. Cerebral palsy has increased in prevalence in middle- and low-income areas as compared with upper class areas (Novak et al., 2017). The prevalence of CP in non-Hispanic black children is higher than non-Hispanic white and Hispanic children; however, the direct cause is not known. It is suspected that racial disparities may result in lower birth rates and prematurity (Stavsky et al., 2017; Van Naarden Braun et al., 2016).

There has been considerable advancement in obstetric and neonatal care during the past three to four decades. Many hoped these advancements would reduce the incidence of cerebral palsy. Unfortunately, the rate has remained relatively stable over this period. This is probably a result of increased survival rates of very low birth weight and premature infants (Novak et al., 2017). CP is 15 times more prevalent in twins, and even more so in triplets, particularly with the surviving infant following an in utero death of the twin (Stavsky et al., 2017). Another factor may be the use of fertility treatments by older women that have resulted in an increase in the number of multiple births. Multiple births tend to result in infants who are smaller and premature and are at greater risk for health problems. On the average, they are half the weight of singleton infants at birth and arrive 7 weeks earlier.

Signs and Symptoms

The early signs and symptoms common to all types of cerebral palsy are abnormal muscle tone, reflex and postural abnormalities, delayed motor development, and atypical motor performance.

Tone Abnormalities

Tone abnormalities include hypertonicity, hypotonicity, and dystonia, which involves abnormal posturing and repetitive, contorted movements. Muscle tone can be characterized as the degree of resistance when a muscle is stretched. For instance, when there is hypotonicity and the elbow is passively extended, there will be little to no resistance to the movement and hypermobility in the elbow joint. With hypertonicity, there will be increased resistance, and it may be difficult to pull the elbow into full extension if the tone is strong. Dystonia presents as involuntary or irregular muscle contractions triggered by several factors, including physiological changes, startle, emotional state, sleepiness, and difficulty with concentration on cognitive tasks (Fehlings et al., 2018). Most infants with cerebral palsy initially demonstrate hypotonia. Later the infant may develop hypertonicity or dystonia, or continue to demonstrate hypotonia, depending on the type of cerebral palsy.

Reflex Abnormalities

With hypertonicity, reflex abnormalities such as hyperreflexia, clonus, overflow, enhanced stretch reflex, and other signs of upper motor neuron lesions are present. Retained primitive infantile reflexes and a delay in the acquisition of righting and equilibrium reactions occur in conjunction with all types of abnormal tone. When hypotonia is present, there may be areflexia, or an absence of primitive reflexes. **Primitive reflexes**, or infantile reflexes, are those involuntary postural responses to static position and movement that should be present during the first several months of life, and it is of concern when they are not. After 4-6 months, primitive reflexes are diminished as righting and equilibrium reactions emerge.

Atypical Posture

The presence of primitive reflexes and muscle tone abnormalities causes the child to have atypical positions at rest and to demonstrate stereotypical and uncontrollable postural changes during movement. For instance, in an infant lying supine with hypertonicity in the lower extremities, the hips are typically internally rotated and adducted and the ankles plantar flexed. This posture is caused by a combination of hypertonicity in the affected muscles and the presence of the crossed extension reflex (Fig. 2.7). In contrast, when an infant with hypotonicity in the lower extremities is lying supine, the hips are typically abducted, flexed, and externally rotated because of low muscle tone, weakness in the affected muscles, and the influence of gravity.

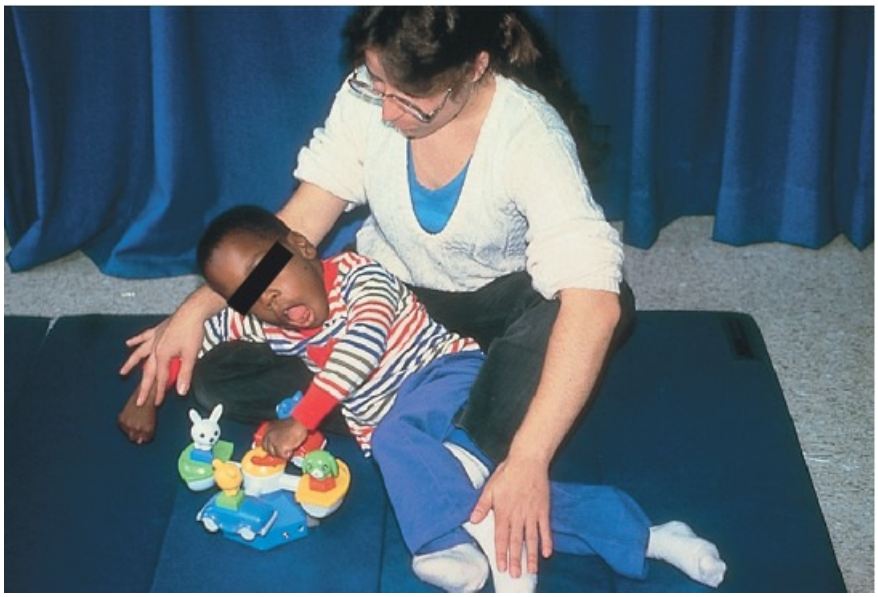

Figure 2.7 Child with spasticity in upper and lower extremities. Note hip adduction and scissoring in his legs, internal rotation at shoulders, fisted hand position, and overflow movements in his mouth. (Reprinted with permission from Hatfield, N. T. (2013). *Introductory maternity and pediatric nursing* (3rd ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.)

Delayed Motor Development

Cerebral palsy is always accompanied by a delay in the attainment of motor milestones. One of the signs that often alerts the pediatrician to the problem is a delay in the child's ability to sit independently or to crawl. While cerebral palsy is often present at birth, it is often not recognized until the child fails to achieve these early motor milestones.

Atypical Motor Performance

The way in which a child moves when performing skilled motor acts is also affected. Depending on the type of cerebral palsy, the child may demonstrate a variety of motor abnormalities, such as asymmetrical hand use; unusual crawling method or gait; uncoordinated reach; difficulty with speech; or difficulty sucking, chewing, and swallowing.

Associated Disorders

In addition to the motor impairments, there are a number of disorders and difficulties associated with cerebral palsy that can significantly affect functional abilities. In some cases, associated disorders can have a more significant impact on function than the motoric aspects of cerebral palsy. The list of possible associated conditions related to cerebral palsy is vast. The most common ones are highlighted here.

Cognitive Impairment

Of all the associated disorders with cerebral palsy, cognitive impairment has the most significant impact upon functional outcomes impacting 50% of the population of children with cerebral palsy. In about one-third of these instances, the cognitive impairment is mild. The most significant impairments most often occur with mixed types and severe spastic quadriplegia (GMFCS IV-V). Children with dyskinetic types of cerebral palsy have the least occurrence of cognitive impairment as compared to motor impairment (Frazier, 2019). It is important to understand that motor limitations and dysarthria may mask cognitive abilities. The onus is on the clinician to provide ample time for a response and work collaboratively to determine the need for and methods to access communication devices.

Orthopedic Conditions

Individuals with cerebral palsy often encounter a wide array of orthopedic issues that are exacerbated by compromised muscular integrity related to spasticity, contractures, hypotonia, and dystonia-related torsion.

Hip displacement and dislocation are another primary concern for children with CP; they often result in pain and reduced quality of life. Hip surveillance, which involves regular, ongoing clinical and radiological examinations, is found to be instrumental for monitoring hip abnormalities. Surveillance should begin at 2 years of age or as soon as cerebral palsy is diagnosed. It should occur more frequently for children with higher GMFCS levels as the incidence of hip dislocation of GMFCS is as high as 90% (Romness & Anciano, 2019; Wynter et al., 2015).

Scoliosis, which is defined as a lateral curvature of the spine, is another condition that may occur across several types of cerebral palsy. Severity is found to correlate with the GMFCS levels and often worsens over time (Romness & Anciano, 2019). It contributes to secondary respiratory and gastrointestinal concerns and can significantly impact quality of life. While surveillance is not yet formalized for scoliosis, ongoing assessment can be beneficial. Low bone density or osteoporosis is often evident making fractures a common concern in children with CP. It is estimated to occur in 20% of nonambulators with CP (Fehlings et al., 2018).

Seizure Disorder

Reports of the incidence of seizures in people with cerebral palsy is noted to be ~41%. The percentage rises to ~67% in those with higher GMFCS levels (Day, Wu, Strauss, Shavelle & Reynolds, 2007). The incidence varies across the diagnostic categories. It is most common in spastic quadriplegia and nonambulatory types. Seventy percent of children with CP and epilepsy experience focal (localized) seizures (Mytinger & Goodkin, 2019).

Visual Impairments

Visual and hearing impairments occur at a higher rate with cerebral palsy than in the general population. Those with CP can have a range of visual issues including those with acuity, strabismus, and visual perception. Cortical vision impairment (CVI) is a complex condition that originates in the visual pathways of the brain associated with lesions common in CP such as PVL. It can manifest as deficits of visual field, acuity, nystagmus, strabismus, visual–cognitive function, and contrast issues. **Nystagmus** refers to rapid, involuntary movement of the eyes, and **strabismus**, or “crossed eyes,” is a condition in which the eyes do not simultaneously look at an object in exactly the same direction. Due to the mixed presentation, neuro-ophthalmological

concerns should be closely followed. It is suspected that CVI occurs in 70% of individuals with cerebral palsy (Fazzi et al., 2012). Visual perceptual impairment is found to be as high as 40%-50% across all types of cerebral palsy and is not specific to one type of cerebral palsy, seizures, or intellectual disability, but rather is more correlated to lower gestational age (Ego et al., 2015). Acuity and oculomotor abnormalities are common in 98%-100% of children with quadriplegia (Fazzi et al., 2012).

Oral Motor and Communication Disorders

Difficulties with oral motor function are commonly present in children with cerebral palsy. They may manifest due to the mechanical difficulties with the act of chewing, swallowing, or speaking. Disturbance in sensation may result in textural aversion to food or inability to manage food within the mouth during the oral phase of eating and swallowing. Dysphagia (difficulty swallowing) may occur due to sensory impairment or as a result of postural and mechanical demands of coordinating all aspects of swallowing, which include the oral, pharyngeal, and esophageal phases (Bickley, Delaney, & Intagliata, 2019). Severe **dysarthria** (difficulty speaking) may affect functional communication, resulting in the need for alternative forms of communication. The Eating and Drinking Ability Classification System (EDACS) (Benfer et al., 2017) and the Communication Function Classification System (CFCS) (Hidecker et al., 2011) offer levels similar to the GMFCS and provide clinicians with a method to classify current functional abilities and limitations for each.

Gastrointestinal

Gastrointestinal difficulties occur frequently in cerebral palsy. **Gastroesophageal reflux** (GERD), which refers to an abnormal, opposite flow of fluid in the esophagus, can create much discomfort and can result in refusal to eat or difficulty transitioning to solid foods. It can also be attributed to additional issues such as anemia, respiratory infections, and weight loss. Pharmacological interventions are often tried first, followed by surgical interventions such as fundoplication which is the surgical reinforcement of the esophageal sphincter (Beinvogl & Mobassaleh, 2019).

Chronic constipation is also evident in those with cerebral palsy due to spasticity of the rectal sphincter. It can result in pain and discomfort and often impacts appetite. It is important for a multidisciplinary team of clinicians along with the patient and caregiver to monitor signs and symptoms of chronic constipation. Interventions such as dietary changes, prophylactics, and enemas are useful to aid in relief (Beinvogl & Mobassaleh, 2019).

Pulmonary

Individuals with complex motor impairments such as spastic quadriplegia often develop respiratory issues that interfere with respiration. The respiratory muscles may be directly restricted or musculoskeletal changes may develop over time. These individuals are prone to frequent upper respiratory infections, reactive airway disease, and sleep disturbances such as sleep apnea, which can significantly impact their health. Progressive changes in the spine, muscle contractures, and changes in the walls of the lungs can contribute to pulmonary disorders (Welsh & Katwa, 2019). Aspiration pneumonia can develop as a secondary issue of gastrointestinal issues noted above due to frequent reflux, poor swallow function, and muscle weakness needed to clear liquids and food with a productive cough. Ongoing, careful assessment

and management of pulmonary function are advisable to monitor risks with respiration and provide pharmaceutical and durable medical equipment as needed.

Diagnosis

The early diagnosis of cerebral palsy was once thought to be difficult. Diagnosis typically occurs between 12 and 24 months; however, research now indicates that accurate diagnosis can occur prior to 6 months adjusted age. Developmental screening and surveillance are crucial to identify concerns in motor abilities early in life. For example, the inability to sit by 9 months, bear weight in the lower extremities, and/or use hands symmetrically should be cause for concern (Maitre et al., 2020; Novak et al., 2017). Following clinical identification, several diagnostic tests are recommended: neonatal brain magnetic resonating imaging (MRI); cranial ultrasound (CUS); genetic testing, which includes phenotyping; developmental testing; and neurological testing (Glader & Stevenson, 2019). Evaluation of gross motor skills is often conducted along with neurological tests such as Hammersmith Infant Neurological Examination (HINE) and Prechtl Qualitative Assessment of General Movements (Kwong, Fitzgerald, Doyle, Cheong, & Spittle, 2018). The combination of the tests noted above can offer up to 98% predictability of cerebral palsy in young children. While early prediction may be arduous, it is necessary to provide early interventions such as hip surveillance and constraint-induced movement therapy (CIMT) (Novak et al., 2017). Because of the high occurrence of associated conditions, children with cerebral palsy should also be screened for cognitive, visual, and hearing impairments, as well as speech and language disorders.

Course and Prognosis

The course of cerebral palsy varies depending on type, severity, and presence of associated problems. With mild motor involvement, the child will continue to make motor gains and compensate for motor difficulties with little to no assistance from caregivers. With more severe forms, little progress may be made in attaining developmental milestones and performing functional tasks. Those with complex cerebral palsy and GMFCS and MACS level V will typically require full-time assistance from a caregiver and need assistive devices such as a custom wheelchair and equipment for activities of daily living (ADLs).

As the child grows older, secondary problems such as contractures and deformities will become more common, especially with spasticity. Adults with cerebral palsy experience musculoskeletal difficulties and loss of function at an earlier age than their nondisabled peers. One study found that walking remains constant in 76% of those who ambulated as a child. Those who used a wheelchair were 34% more likely to quit ambulating by age 25 (Day et al., 2007).

The survival rate for adults with cerebral palsy is good but lower than the general population. An increase in mortality is evident with higher level of GMFCS and typically attributed to secondary conditions. An Australian study of 385 persons found that 75% of mortality cases were attributed to respiratory reasons such as pneumonia, with an average age of 14.6 (Blair, Langdon, McIntyre, Lawrence, & Watson, 2019).

Medical/Surgical Management

Because of the complexity and diversity of difficulties affecting the individual with cerebral palsy, medical management requires a team approach using the skills of many professionals. Depending on the type of cerebral palsy and the presence of associated problems, team members typically include medical doctors from a variety of specialties, occupational therapist(s), physical therapist(s), speech pathologist(s), an educational psychologist, a nurse, and social worker(s). The emphasis of intervention is to help the child gain as much motor control as possible, position the child to maximize independence and minimize the effects of abnormal muscle tone and pain, instruct the parents and caregivers on handling techniques and ways to accomplish various activities of daily living, recommend adaptive equipment and assistive technology to increase the child's ability to perform desired activities, provide methods to improve feeding and speech if difficulties are present, and help parents manage behavioral concerns and family stresses. The primary physician treats the usual childhood disorders and helps with prevention of many health problems. Physicians with various medical specialties may also be involved. The neurologist may assess neurological status, conduct gait analysis, address tone pharmacology needs, and help control seizures, if present. An orthopedist may monitor skeletal changes, prescribe orthotic devices, and address any necessary surgeries. A gastroenterologist may monitor food intake, reflux, and needed surgical intervention. An ophthalmologist would assess and treat any visual difficulties.

Medical management includes both surgical and nonsurgical approaches, with much of the focus on techniques to decrease spasticity and dystonia. Several oral medications such as diazepam (Valium), dantrolene (Dantrium), and baclofen are used to reduce spasticity in severe cases with mixed results (Delgado et al., 2010). Intrathecal baclofen infusion (ITB) administered through a pump implanted in the abdominal wall to the spinal cord fluid has shown to be more effective than oral medications in reducing severe spasticity and dystonia in cerebral palsy. Impact on spasticity of the lower extremities have shown to be positive; however, effect on the upper extremities is inconclusive. Complications from surgery occur in 5 in 100 cases. Further evidence is needed to determine significance for quality of life (Novak et al., 2013; Russman, 2010). Another treatment more widely used in recent years is the injection of botulinum toxin (brand names Botox or Dysport) into muscles. Spasticity is reduced for a period of 3-6 months after injection. Botox or Dysport is injected into specific muscles that, in addition to reducing tone, increases range of motion and reduces deformities as well as provides an opportunity to work on muscle strengthening. A systematic review of interventions found that Botox is effective for decreasing upper extremity spasticity, improving walking and hand function, and decreasing drooling (Novak et al., 2013).

Orthotics and splints may be prescribed for the child with cerebral palsy. Upper extremity splints are worn to maintain range of motion, manage contractures, or facilitate typical grasping patterns during daily activities. A thoracolumbosacral orthosis (TLSO) is a back brace used to support the trunk and slow the progression of spinal deformities. Ankle–foot orthoses (AFOs; Fig. 2.7) and supra malleolar orthotics (SMOs) offer ankle stability, prevent collapse of the arch, and facilitate proper foot alignment. Orthotics and splinting should be used with caution as the evidence is insufficient that it improves function and prevents contractures and deformities. Child and caregiver burden, wearing-schedule compliance, and risk of skin integrity issues related to orthotics or splints should also be considered. Serial (or progressive) casting is shown to be effective for improving range of motion in the lower extremities, but there is insufficient

evidence that it is equally effective in the upper extremities. However, CIMT, which involves restraint of the unaffected limb in conjunction with bimanual training (use of both hands together with repetitive activities), is proven to be effective for cerebral palsy intervention (Novak et al., 2013).

Surgical approaches are used to improve the function and appearance of affected areas of the body and to prevent or correct deformities. Common surgical procedures include joint fusions, tendon lengthening to increase range of motion, and tendon transfers to decrease spastic muscle imbalances (Koman & Smith, 2014). Selective dorsal rhizotomy (SDR) is a neurosurgical technique that is used to reduce spasticity and improve function in carefully selected individuals (Ferger, Lunsford, Sauer, Novicoff, & Abel, 2015; Tedroff, Hägglund, & Miller, 2020). The procedure involves dividing the lumbosacral posterior nerve root into four to seven rootlets. Each rootlet is stimulated electrically. The dorsal rootlets causing spasticity are determined through careful neurological examination of those showing pathology. This approach is highly invasive with mixed results. Often, other pharmacological interventions such as baclofen or Botox are still required following the procedure (Tedroff et al., 2020). For children with diplegia, the goal is to improve gait and leg function. For children with spastic quadriplegia who have very limited movement, the goal is to increase their independence by allowing them to sit for longer periods of time, enabling them to use a wheelchair or potty chair and making daily care easier for their caregivers by reducing the spasticity that makes dressing and other daily living tasks more difficult. An essential part of this treatment approach includes intensive postsurgical physical and occupational therapy for a period of several weeks.

Impact on Occupational Performance

It is important for the occupational therapist to be aware of all the client factors that can affect individuals with cerebral palsy, but to not make any assumptions based on the type of cerebral palsy and known associated disorders. Each factor should be directly assessed to determine its impact on occupational performance. Furthermore, each individual is unique and will have their own set of strengths and challenges. Factors such as motivation, cognition, caregiver support, socioeconomic status, and environmental contexts will play a role in participation in occupation. Virtually all of the body function categories can be affected in the individual who has cerebral palsy. Milder forms of cerebral palsy may have limited impact upon occupational performance. Some individuals will require physical assistance, additional training, or assistive technology to participate fully in occupational performance areas, while individuals with severe forms of cerebral palsy will be limited in their performance of all areas of occupation. The body function category that is always affected in individuals with cerebral palsy is neuromusculoskeletal and movement-related function. Overall, the severity of the condition, type of cerebral palsy, and the presence of associated disorders determine how occupational performance is impacted.

Activities of Daily Living and Instrumental ADLs

Participation in activities of daily living (ADLs) and instrumental ADLs varies greatly depending on classification of cerebral palsy and severity of the condition. Many children and adults with cerebral palsy can successfully manage all essential self-care activities. Children and adults with a GMFCS and MACs V will require assistance for nearly all ADLs and IADLs from a caregiver,

nurse, or paraeducator while at school. Additionally, consideration of accessibility of everyday items within the lived environment will help foster independence. For example, adaptations can be made to the counter level in the kitchen and bathroom to help promote participation in daily routines and meal preparation. Likewise, environmental controls needed to manage the lights, television, or small appliances can be programmed through communication devices for youth and adults with spastic quadriplegia.

Health Management

As the youth with cerebral palsy transitions into adulthood, health management becomes a primary concern. It is important to establish health and wellness routines such as medication and appointment management, wellness and stress-reduction strategies, and fitness regimes as early as possible. Independence with health care decisions varies greatly depending on functional level and other factors discussed in this chapter. Health care decisions automatically transfer to youth at 18 years of age; therefore, planning for health care needs should be considered in the early to mid-teens (de Gusmao & O'Hare, 2019). It is also necessary to transition from pediatric care to an adult primary care physician and specialists. The youth and caregivers should be prepared for the change in focus from comprehensive chronic care to that specifically targeting acute concerns. Therapies, private duty nursing, and habilitation services may no longer be covered by insurance for the adult with cerebral palsy.

Rest and Sleep

Rest and sleep may be difficult for many with cerebral palsy. This is due to several reasons, including pain, dystonia triggered by movement in the night, seizures, respiratory issues, and/or sleep apnea (Welsh & Katwa, 2019). Disruption of rest and sleep for the child or youth with cerebral palsy may also significantly impact that of the caregiver's due to possible medical needs throughout the night. Goal planning focused on sleep and rest strategies may be beneficial for some with mild sleep disturbances. Activities such as reduction of screen time before bed, sleep schedules, and naps can help facilitate healthy sleep patterns.

Education

Children and adults with cerebral palsy who are participating in education may require minimal to full assistance. Those with lower GMFCS levels may need little to no assistance to participate but may need assistance to transition to classes and need minimal accommodations for assignments. Someone with spastic quadriplegia may require full assistance throughout the day for transfers, assistive technology for communication and learning activities, and school nursing for feeding and bowel/bladder management. Both global and specific mental functions can be affected, particularly if there is an associated learning disability, attention deficit hyperactive disorder, or cognitive impairment.

Work

Many with cerebral palsy are able to lead a full productive work life. Employers may need to provide simple environmental modifications (eg, provision of a stool for a cashier) for those with mild variations of cerebral palsy (GMFCS I-II). Individuals with spastic quadriplegia and limited

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