Definition and classification of cerebral palsy: A historical perspective

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Definition and classification of cerebral palsy: a historical perspective

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The definition of a diagnosis identifies explicitly which cases are to be recorded under that term and, by implication, which are to be specifically excluded. The definition is the basis for planning treatment and for counting cases in a population. Classification within a diagnosis categorizes those cases with similar characteristics together and distinguishes those cases with diverse features apart. The design of a classification system, for instance whether it is organized into nominal or ordinal categories, will vary depending on the concept being classified and intended purpose for which classification is being made. The most frequently cited definition of cerebral palsy was published by Bax (1964) as 'a disorder of posture and movement due to a defect or lesion in the immature brain'. The label does however encompass a variety of syndromes and some, therefore, prefer the term *cerebral palsies*.

Cerebral palsy (CP) is now familiar to most health and social service professionals, as well as to many members of the general public, as a physically disabling condition. In fact, although CP only affects between 2 and 3 per 1000 live births, it is thought to be the most common cause of serious physical disability in childhood (Surveillance of Cerebral Palsy in Europe 2000). Historically, CP was predominantly studied in relation to the pathology and aetiology of the impairment. Discussion regarding the definition and classification of CP was first recorded in medical literature during the nineteenth century, predominately in French, German, and English language publications. However, what exactly the term 'cerebral palsy' describes has been debated for more than 150 years, and discussions about how the different manifestations of CP can be best classified continue to the present day.

Before 1900

The quest to correlate brain lesions with their clinical manifestation began with early French publications by pathologists debating the association of hemiplegia of the body with hemiatrophy of the brain identified by post-mortem (Lallemand 1820, Cazauvieilh 1827 [as cited in Ingram 1984]). However, the seminal work describing *cerebral paralysis*, and particularly the related musculoskeletal issues, was elucidated by an English orthopaedic surgeon named William Little in one of a series of lectures in 1843 entitled 'Deformities of the Human Frame'. Whilst his lectures focused on joint contractures and deformities resulting from long-standing spasticity and paralysis, Little clearly indicated that the cause of the spasticity and paralysis was often damage to the brain during infancy, and specifically preterm birth and perinatal asphyxia (Little 1843). Little also noted that behavioural disorders and epilepsy were only occasional complications and not central to the condition.

At about the same time, a German orthopaedic surgeon, von Heine, was reporting similar clinical syndromes as a result of infections such as scarlet fever and vaccinations (von Heine 1860). He cited the work of his compatriot Henoch, who had written his dissertation several years earlier, describing hemiplegia in children (Henoch 1842). It has been suggested that it was actually von Heine, rather than Little, who first distinguished CP from the flaccid paralysis caused by poliomyelitis (Osler 1889, Bishop 1958). However, Little was known to have spent some years studying in Germany during the 1830s and it is possible that there was some cross-fertilization of ideas, although this is not formally recorded. Regardless, CP was known for many years after as 'Little's Disease'.

In his best known work, published in 1862, Little expands on the association between a large number of his patients' clinical presentation and their birth history as recalled by the family (Little 1862). Little differentiated between the congenital deformities observed at the time of birth, such as falipes equinovarus, and the limb deformities that developed subsequent to preterm, difficult, or traumatic births, due to what he termed spastic rigidity. He demonstrated his familiarity with the work of French, German, and Irish pathologists in constructing his theory. Little grouped the clinical presentation of 47 cases as either: (1) hemiplegic rigidity affecting one side only, although lesser impairment of the apparently uninvolved limb was frequently observed; (2) paraplegia affecting both legs more than arms; and (3) generalized rigidity. Little showed careful consideration for his audience in the

published discussion by conceding to the President of the Obstetrical Society of London that for every 'one (case) that depended on abnormal or premature labour there were twenty or more from other causes incidental to later life'. Sarah McNutt, an American physician, continued to raise the profile of the risks of long-term disability arising from birth trauma (McNutt 1885). Notably, the American Neurological Association admitted her as their first female member; but the content of her lectures apparently made her unpopular with some eminent obstetricians whilst she was on a tour in the UK (Ingram 1984).

At the time he was resident in America, the eminent Canadian William Osler published articles in 1886 and 1888 before his more notable monograph was published in London in 1889. 'The Cerebral Palsies of Children' comprehensively described his study of a case series of 151 patients (Osler 1889). Osler acknowledged the contributions from his German, French, English, and American colleagues and stated that he would 'for clearness and convenience adhere to custom and classify cases according to the distribution of the paralysis, whether hemiplegic, diplegic or paraplegic'. In fact, he classified his cases into the three categories but used the terms: (1) infantile hemiplegia; (2) bilateral spastic hemiplegia; and (3) spastic paraplegia. Osler references the synonym *spastic diplegia* for bilateral spastic hemiplegia to Samuel Gee at St Bartholomew's Hospital in London. William Osler later moved from Pennsylvania to become Regius Professor of Medicine at the University of Oxford and was knighted in the UK for his contributions to medicine.

In the year following Osler's seminal book, the neurologists Sachs and Peterson published their series of 140 cases (Sachs and Peterson 1890). They contrasted the comprehensive understanding that had then been achieved regarding the clinical symptoms and pathology of poliomyelitis with the dearth of understanding about CP. Sachs and Peterson followed the convention of the time by using the same classification system as Osler: hemiplegic, diplegic, or paraplegic. Where possible, they investigated aetiology using post-mortem examinations but concluded that any of the three clinical presentations could result from a variety of causes. Despite this lack of correlation they advocated that classification should include 'special reference to the pathology of the disease'.

Sigmund Freud was of the opposite opinion (Freud 1893). Despite his background in neuropathology, he advocated classifying CP using only clinical findings. Freud recognized that, even with post-mortem examination, the pathological findings resulted from a combination of the initial lesion and repair process and, therefore, were only partially related to the clinical manifestation. His classification system combined previously separate categories under the single term 'diplegia' for all bilateral disorders, as distinct from hemiplegia. The term diplegia was used to describe generalized rigidity of cerebral origin, paraplegic rigidity, double spastic hemiplegia, generalized congenital chorea, and generalized athetosis. Athetosis had already been described, initially by Hammond, as involuntary writhing movements in adults affected by hemiplegia (Hammond 1871), and it would later be more clearly differentiated from other movement disorders by Gowers (1876). Freud's observations regarding aetiology identified three groups of causal factors: (1) maternal and idiopathic congenital; (2) perinatal; and (3) post-natal causes. He noted that it was difficult to know whether later problems resulted from birth trauma, as described by Little, or whether in fact there were predisposing factors that may have caused these infants to have difficult births. He thought the task of separating congenital from acquired cases impossible in some cases and generally unhelpful. Freud was aware that children with ataxic symptoms might require a separate group, as became the case after the work of Batten (1903), but at the time of his writing he had not seen enough cases of non-progressive ataxia to be sure.

Freud lost interest in CP and instead focused on his study of psychoanalysis (Accardo 2004). Nevertheless, his influence was such that his lasting statements regarding the futility of attempting to associate clinical syndromes with neuropathology may have predisposed to the dearth of research about CP during the first half of the twentieth century. Also, at that time, poliomyelitis and tuberculosis were more common causes of disability and, therefore, attracted greater attention from medical researchers.

From 1900 to 2000

In the early 1920s, some 30 years after Freud's comments, an American orthopaedic surgeon made the next major contribution to our understanding of CP (noted by Mac Keith and Polani 1959). Winthrop Phelps pioneered modern approaches to the physical management of children with CP advocating physical therapy, orthoses, and nerve blocks. In a later article Phelps identified his four treatment goals: locomotion, self-help, speech, and general appearance (Phelps 1941). His approach to surgery was conservative. Phelps acknowledged the need for a neurological classification system for diagnostic purposes but preferred to use his own classification system as a basis for treatment. He proposed that classification should be made on a functional basis including both mental and physical ability, and that a social assessment should precede treatment. Phelps grouped all movement disorders under the term dyskinesia, and used spasticity, athetosis, overflow or synkinesia, incoordination or ataxia, and tremor as sub-categories. He noted that these five varieties rarely occurred in pure form. Phelps helped to found the American Academy for Cerebral Palsy in 1947 and was elected its first president. The Academy's mission remains 'to foster and stimulate professional education, research, and interest in the understanding of these conditions and in improving the care and rehabilitation of affected persons' (American Academy for Cerebral Palsy and Developmental Medicine 2005).

American neurologist Myer Perlstein recognized the prevailing confusion regarding classification of CP and contributed a lucid account of the various systems that existed in the 1940s and 1950s (Perlstein 1952). He recounted methods for classifying children according to the anatomical site of the brain lesion, clinical symptoms, degree of muscle tone, severity of involvement, and aetiology. Thus, he suggested that a modular description using components from each category can be assembled. Minear conducted a survey with the members of the American Academy for Cerebral Palsy in 1953 and published the resulting classification system based on their majority opinion (Minear 1956). He defined CP simply as any 'symptom complex' arising from non-progressive brain lesions. Minear's system is similar to Perlstein's in that it is more of a comprehensive listing of all clinical symptoms

with categories for motor impairment, topography, aetiology, supplemental, neuro-anatomical, functional capacity, and therapeutic requirement. A separate dimension for functional capacity with four levels is included in the classification but used undefined terms such as mild and moderate limitation of activity.

Meanwhile in the UK, the classification systems used to describe case series by Evans (1948) and Asher and Schonell (1950) comprised different combinations of topography and motor impairment. Wyllie (1951) used a confusing combination of neurological and aetiological criteria to define categories which were: (1) congenital symmetrical diplegia; (2) congenital paraplegia; (3) quadriplegia or bilateral hemiplegia; and (4) hemiplegia. The selected category was supplemented with a statement of the type of motor disorder: spastic, flaccid, mixed, athetoid, or ataxic. Harking back to Freud's argument that it was not possible to classify using aetiology, Ingram preferred a system using neurological and topographical categories, supplemented with an indication of the severity using the terms mild, moderate, and severe (Balf and Ingram 1955). The Ingram classification separated hemiplegia, double hemiplegia, and diplegia from ataxic and dyskinetic categories. Ingram grouped involuntary movement disorders, such as dystonia, chorea, and athetosis, under the term dyskinesia. Ingram pointed out that transient changes in muscle tone seen consistently in children with diplegia would require their continual reclassification if the terms 'rigidity' or 'spasticity' were used as categories.

Again in the UK, in 1957 Mac Keith and Polani convened an informal group called the Little Club that was dedicated to thinking through the terminology for describing CP. The Little Club published its definition of CP as 'a permanent but not unchanging disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development' (Mac Keith and Polani 1959). The Little Club classification uses the term 'spastic' with sub-categories of hemiplegia, double hemiplegia, and diplegia; the other categories were dystonic, choreo-athetoid, mixed, ataxic, and atonic CP. Ingram continued his aforementioned criticism citing the changes observed in the series of 1821 patients by Bronson Crothers (Crothers 1951) that would require cases to be moved continually between classification categories (Ingram 1984). Some of the original Little Club members refined the definition of CP as 'a disorder of posture and movement due to a defect or lesion of the immature brain' and 'for practical purposes disorders of short duration, due to progressive disease or due solely to mental deficiency were excluded' (Bax 1964). The group noted the inconsistent interpretation of terms such as 'spastic' between different professional and country cultures. These inconsistencies precluded further progress which led to their conclusion that, at that time, it was 'impossible to proceed definitively with classifying cerebral palsy' (Bax 1964).

In the 1980s, another expert group commissioned by the Spastics Society (now SCOPE) discussed how to classify CP from an epidemiological perspective (Evans and Alberman 1985; Evans et al. 1986, 1987). Evans' group were particularly interested in monitoring rates of CP in populations as public health markers of perinatal and neonatal health care. Their approach built upon earlier work by Fiona Stanley and others in Western Australia for a 'limb-by-limb' classification system. The subsequent 'Evans form' recorded details of central motor deficits in terms of the neurological type: (1) hypotonia; (2) hypertonia (including stiffness, spasticity, and rigidity); (3) dyskinesia; and (4) ataxia (Evans et al. 1987). A decision was made to record details of each limb and the head and neck separately. The 'Evans form' also enabled recording of functional mobility and manual dexterity in one of four ordinal levels, the presence of intellectual and sensory impairments, communication difficulties, seizures, congenital and acquired malformations, as well as genetic and other disorders. Some effort was made to validate this system, with repeated meetings showing videos to test inter- and intraobserver, and within and between patient variations. However, details of the reliability and validity of their classification were not widely disseminated.

A summary of several meetings held in Europe and America between 1987 and 1990 was published by Mutch et al. (1992) resulting in a further revised definition to underline the heterogeneity of the condition: 'an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development'. Notably this annotation also included a revised Swedish classification system which, whilst still not perfect, offered simplicity as its major asset. The three neurological categories were spastic, ataxic, and dyskinetic; these were subcategorized in mixed ways as hemiplegia, tetraplegia, or diplegia for spastic cases; as either diplegic or congenital for ataxic cases, and as either mainly chorioathetotic or mainly dystonic for dyskinetic cases. Whilst noting that at the time it remained beyond their capability, the authors resuscitated the yearning for an aetiologically-based classification system (Mutch et al. 1992).

The Gross Motor Function Classification System (GMFCS) was developed in response to the need to have a standardized system for classifying the severity of movement disability among children with CP (Palisano et al. 1997). Previous descriptive systems had included three levels, such as: (1) *mild, moderate,* or *severe*; or four levels such as (2) *non-ambulatory or physiological, household* and *community walkers* (Hoffer 1973); and (3) the Evans system: *not walking, restricting lifestyle, functional but not fluent*, or *walks fluently* (Evans and Alberman 1985). A five level description of children's ambulatory ability was reported by Hutton et al. in their study of factors affecting life expectancy, though they collapsed the data into only two categories of 'walking' and 'not walking' for their analyses (Hutton et al. 1994). However, there was no evaluation of the validity and reliability of any of these systems until the development of the GMFCS.

Palisano and his colleagues used the underlying construct of self-initiated functional abilities in sitting and walking and the need for assistive devices, such as walkers or wheelchairs, to develop the GMFCS and systematically tested its validity and reliability (Palisano et al. 1997, Wood and Rosenbaum 2000). The GMFCS describes movement ability of children with CP in one of five ordinal levels. The GMFCS currently includes descriptions of children's abilities for each level across four age bands: less than 2 years, 2 to 4 years, 4 to 6 years, and 6 to 12 years, with an adolescent age band currently under development. Children in Level I can perform all the activities of their age-matched peers, albeit with some difficulty with speed, balance, and coordination; children in Level V have difficulty controlling their head and trunk posture in most positions and

achieving any voluntary control of movement. The GMFCS has now become the principal way to describe the severity of motor disability for children with CP. The system has had good uptake internationally and across the spectrum of health care professions for use in research and clinical practice by providing a system for clearly communicating about children's gross motor function (Morris and Bartlett 2004).

From 2000

Following a survey of practice across the continent, the group for the Surveillance of Cerebral Palsy in Europe (SCPE) published their standardized procedures for ascertaining and describing children with CP for registers and databases (SCPE 2000). The definition was largely a reiteration of that proposed by Mutch and colleagues (Mutch et al. 1992) and included five key points. CP is: (1) an umbrella term; (2) is permanent but not unchanging; (3) involves a disorder of movement and/or posture and of motor function; (4) is due to a non-progressive interference, lesion, or abnormality; and (5) the interference, lesion, or abnormality is in the immature brain.

The system adopted by SCPE provides a decision flow chart to aid classification into neurological and topographical categories including spastic (unilateral or bilateral), ataxic, dyskinetic (dystonic or choreo-athetotic), or not classifiable. Clearly defined symptoms and requirements are provided for each neurological category. Despite careful planning of the system, there has been little work to demonstrate the validity and reliability of classification. The lack of any defined criteria for recording functional limitations in the SCPE definition was noted by Lenski et al. (2001). Subsequently, SCPE, along with other research groups, demonstrated that the inclusion of a description of functional ability markedly improved the reliability of diagnosing children with CP (Paneth et al. 2003). Consistent application of the diagnosis is of paramount importance when the prevalence of CP from different sources and places is being compared.

There has also been further progress in classifying children's motor abilities. The Manual Ability Classification System (MACS) now provides a method analogous to the GMFCS for classifying the ability of children with CP to handle objects (Eliasson et al. 2006). The Functional Mobility Scale (FMS) has been devised as an evaluative system to measure changes in walking ability, such as might be seen following intervention (Graham 2004). The FMS enables a child's performance over three distances (5, 50, and 500 metres) to be classified by their need for assistive devices such as a wheelchair or walking aid. In contrast to the GMFCS, where a child's level would not be expected to change, significant changes in FMS levels have been observed following orthopaedic surgery. This joins the battery of outcome measures to evaluate treatment for children with CP such as the Gross Motor Function Measure (Russell et al. 2003).

With rapidly improving imaging technology there is renewed interest in aetiological classification systems correlating clinical syndromes and neuroanatomy, challenging Freud's 100-year-old statement that this task was futile. Progress has been made using ultrasound and magnetic resonance imaging (MRI) to detect structural impairments of the brain before they manifest as movement disorders (Accardo et al. 2004). MRI can also be used to approximate the timing at which the brain was damaged, based on normal neurodevelopmental stages (Barkovich 2002, Krägeloh-Mann 2004). Only partially explained to date, Krägeloh-Mann (2004) summarizes some of the correlations that are emerging between the timing and location of the lesion and functional, cognitive, and sensory impairments.

The search for a single internationally accepted definition of CP continues. Another international multidisciplinary group met in 2004 and some of those participants then revised the oft-cited definition by Bax (1964) to recognize that the key motor deficit is often accompanied by other neurodevelopmental impairments. Their new definition is:

> Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems. (Modified after Bax et al. 2005)

Whilst welcoming the debate and the desire for consensus, the new definition received mixed reviews in the accompanying editorials. Carr (2005) described how the proposed definition and classification would affect clinical practice and the challenge of shifting from traditional modes of thinking; Blair and Love (2005) considered the precision of the definition to be flawed in the same way as previous attempts, particularly from an epidemiological perspective. Chiefly, they point out that the term 'non-progressive' was no more clearly defined than before, neither were the age limits and lower limit of severity for inclusion, or what syndromes should specifically be excluded. However, Blair and Love did not themselves provide any suggestions of how to address these issues. Whilst the precision with which the definition is applied by clinicians may have negligible consequences for treatment, the implications for measuring rates of CP over time are more profound.

So, in summary, after more than 150 years of debate we do not yet have a universally accepted definition of CP; nor do we have an agreed method for classifying the impairment that has been shown to be robust in terms of validity and reliability. It would be ungracious, however, not to pay a respectful tribute to those illustrious and often remarkable people who have all in their own way strived to further the scientific study of CP. In contrast, there has been more progress in classifying children's movement and manual abilities as these are probably easier to observe and categorize. The GMFCS has been adopted widely to classify movement ability and perhaps demonstrates that testing the fundamental properties of the validity and reliability of classification systems vastly enhances their credibility. To move the scientific study of CP forward we now need to examine how well the recent definitions and classifications proposed by SCPE and Bax's group actually perform in practice.

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