Point of view

An overview of dyslexia

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Background
Dyslexia is a specific learning disorder which persists lifelong. Due to its impact on academic performance, the majority of affected children can experience long term educational, societal, psychological, emotional and financial adversities. Sri Lanka, as a third world country, still does not have a national level programme for identification and management of dyslexia. Very limited knowledge of healthcare workers, preschool and primary school teachers have resulted in delayed identification. It is vital to diagnose the condition as early as possible and initiate early intervention for a better prognosis. Therefore, it is timely for clinicians who work with children to be aware of the condition, its early identification and implementing early interventions.

What is dyslexia?
The concept of dyslexia has been given different explanations worldwide. However, a universally accepted definition of the concept has not been found so far. International Dyslexia Association (IDA) defines dyslexia as "A specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction"[1].

In Diagnostic and Statistical Manual of Mental Disorders (DSM 5), dyslexia is graded as a specific learning disorder indicated by "Inaccurate and effortful word reading, difficulty of understanding the meaning of what is read and difficulty with spelling. These difficulties must have persisted for at least six months and remain below the skills expected for the chronological age. The difficulties are not better accounted for by intellectual disabilities, uncorrected visual or auditory acuity, other mental or neurological disorders, psychological adversity or lack of proficiency in the language of academic instruction, or inadequate educational instruction[2].

Historical background
Adolph Kussmaul (1822-1902), a German Professor of Medicine, first identified the difficulties in recognizing words entitling them Wortblindheit (word-blindness). In 1877 the word 'dyslexia' was introduced by a German ophthalmologist, Rudolf Berlin, who observed some of his adult patients having difficulties in reading while having normal vision. He attributed physical changes in the brain as the reason for it. The name 'dyslexia' originated from the Greek words 'dys' (inadequate or poor) and 'lexis' (language or words). In 1896 Dr. William Pringle Morgan, a British physician, published the first case report of a child with developmental dyslexia. He described a 14 year old boy, Percy F, an intelligent and bright child who was very good at games but had severe difficulties in reading[3]. In 1092 the neurologist, Samuel Orton, described the neurological basis for the disorder, that delay in development and specialization of the left hemisphere for language was potentially causal[3].

Incidence and prevalence
Dyslexia has been widely studied in western countries during the last few decades. Its prevalence is estimated to range from 5% to 17% among school-aged children[4]. A population based study in Rochester, Minnesota, reported cumulative incidence rates of reading difficulties to range from 5% to 11% according to the formula used[5]. However, estimation of dyslexia prevalence can be challenging due to different presentations of the condition in different languages, different assessment tools and the presence of different variants and ranges.

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Aetiology

Reading is a complex skill acquired by integration of multiple processes like vision, language cognition and attention. Multiple theories have speculated on the development of dyslexia. The *phonological deficit theory* describes those deficits in storing, representing or retrieving phonemes as the reason for poor reading[6]. *Rapid auditory processing theory* explains that auditory deficits in perceiving short/rapidly varying sounds as the reason[7]. *Visual deficit theory* suggests those deficits in visual magnocellular system and its connection with the posterior parietal cortex as the reason for dyslexia[8]. According to the *cerebellar deficit theory*, the deficit in cerebellum is responsible[9]. The 'Causal Modeling Framework', formulated by two developmental psychologists, John Morton and Uta Frith, in 1995, is a major tool which compares different theories about development disorders and gives the common association between them. This framework explains three levels: the cognitive level, biological level and the behavioural level. According to this framework all three are equally important and integrated to each other[10].

The aetiology of Dyslexia is multifactorial, comprising genetic, neurobiological, cognitive and environmental factors.

Neurobiological factors: Neuroimaging methods have identified left inferior, frontal superior, temporo-parietal and middle temporal regions as brain areas mainly involved in single word reading in a normal adult[11]. Structural imaging studies and post-mortem studies on brain structure have shown small or symmetric peri-sylvian language areas in dyslexics relative to controls[12]. However these studies have limited consistency.

Psychological factors: The main psychological causal mechanisms for dyslexia are weaknesses in phonological awareness[13] and rapid automatized naming[14]. The deficits in basic perceptual processes such as perceptual learning deficits, visual-spatial attention and temporal processing[15] are also identified as causal factors.

Genetic factors: Developmental dyslexia is highly heritable and familial, involving multiple risk factors, both genetically and environmentally[16]. Accumulating evidence has shown association with multiple candidate dyslexia genes like KIAA0319 and DCDC2 at DYX2, DYX1C1 at DYX1, ROBO1 at DYX5, MRPL19 and C2orf3 at DYX3 and KIAA0319L at DYX8[17]. Many of these genes are involved in neuronal migration, axon guidance and neural development[17].

When considering the gene and environmental risk factors for dyslexia, it is very important to focus on gene–environment correlation of the parental genes working through the environment. It is not surprising that a parent's genotype is associated with both the child's genotype (genetic risk) and the poor literacy environment due to poor parental reading skills[18].

Environmental factors: Apart from gene-environment correlation, there are multiple environmental risk factors identified for dyslexia. According to the emergent literacy perspective, reading cannot be acquired as an isolated developmental stage. It is difficult to demarcate the boundary between pre-reading and reading. It suggests that the "Home Literacy Environment" (literacy-related attitudes and stimulation that preschool children receive at home) can be a determinant of their future success as readers. Home Literacy Environment is not a simple construct, but rather a range of attitudes, beliefs and practices within the home environment, which operate at different levels on a child's development. This is unlikely to be purely a "passive" influence for the child, it is rather a bidirectional process. For example, if a child is enjoying reading and well engaged, it is likely that a responsive parent would be motivated to read more with that child[19]. The socio-economic status of the family also predicts the parental attitudes towards reading, types of parent-child interactions and children's early interest in books[19]. Studies have suggested a stronger association between higher socio-economic status and a larger vocabulary. Level of family stressors, family resilience to stress and discipline practices at home may interfere with child development in multiple ways[19].

Associated comorbidities

It is evident that dyslexia can be comorbid with other neurodevelopmental disorders such as attention deficit hyperactive disorder (ADHD), attention deficit disorder (ADD), dyspraxia, Tourette syndrome and obsessive-compulsive disorder (OCD)[20]. It is estimated that 20-40% of children with ADHD can have dyslexia[21]. In addition, nearly 85% of children with developmental coordination disorder (dyspraxia) can experience reading difficulties[20]. A study has shown that 1 in 7 children with Asperger syndrome can have dyslexia[22]. There is a strong association between dyslexia and language disorders as both are characterized by poor phonology. Nearly 50% of dyslexic children can have language disorders and dyslexia is present in nearly 50% of children with language disorders[23]. Since speech and language problems usually precede problems with reading, it can be considered as a red flag sign for dyslexia[24].

Dyslexia paradox

'Dyslexia paradox' is the gap between the earliest age at which the identification is possible and the age at which detection and management typically occur[25]. This can delay the child accessing effective

interventions and result in profound academic and socio-emotional implications. Currently, in most countries, dyslexia is diagnosed at school grade 2-3 or later[26]. Unfortunately, by the time they are diagnosed, they have already failed to learn reading over a long period and have fallen behind their peers academically[26]. This "wait-to-fail" approach can delay initiating interventions during the most effective window period for interventions with heightened brain plasticity, which is considered to be kindergarten and first grade[26].

Consequences of untreated dyslexia

Untreated dyslexia can seriously impact various aspects of children like communication, education, career and mental health. It is evident that untreated dyslexia can lead to poor academic performance. Prolonged academic failure and perceived low self-esteem can increase the risk of anxiety and depression[27]. Therefore, it is possible that a depressive disorder is diagnosed in a child with undiagnosed dyslexia, which may be antecedent and causative, hiding the primary focus for management. Dyslexia may contribute to school refusal in children as their experience related to poor academic performance can make school an unpleasant place[28]. Some dyslexics can have fear of failure, which can lead to avoidance of reading which further aggravates the problem. This is named as the 'Matthew effect of reading'[28]. Dyslexic children are less likely to complete school and enroll in higher education[29]. Dyslexic adolescents have shown increased rates of aggression, externalizing behaviour and delinquent behaviour over their peers with normal reading[30]. Furthermore, they are at higher risk of getting engaged with the juvenile justice system and nearly 28-45% of incarcerated youth have a learning disability[31].

Early predictors of dyslexia

Considering the importance of early identification and intervention, and the many unfavourable consequences that can be prevented or mitigated, it is clear that there is a great potential therapeutic value in early identification of risk factors for dyslexia in children. Home literacy environment can be a good predictor for development of early reading skills. Given the high heritability, family history is identified as a major risk factor. Due to the strong association between dyslexia and language disorders[23], poor speech development can also be considered an early predictor. Reading relies on fast visual processing of sequential stimuli. An Italian study has shown that poor visual spatial attention in kindergarten children is a predictor of poor reading[32]. Non-verbal intelligence is considered an indicator of identification and diagnosis of dyslexia. Reading achievement and intelligence quotient (IQ) discrepancy models have been used historically to diagnose dyslexia. Surprisingly, some new studies have shown stronger genetic association between reading difficulties and higher IQ[33]. It has also been suggested that IQ can be a protective factor for dyslexia that can be successfully remediated. The working memory is involved in the storage and active processing of ongoing information. Working memory is also identified as a weak but still noteworthy predictor of reading[34]. As dyslexia can be comorbid with other neuro-developmental disorders like ADHD, ADD, OCD, dyspraxia and Tourette syndrome[20], it is important to look for dyslexic features in children with neuro-developmental disorders.

The role of a clinician in early identification of dyslexia

Early identification and early intervention are pivotal for a good prognosis and for reducing 'dyslexia paradox'. It is clear that medical officers who work with children have a vital role in this. They should be aware about this condition and focus on risk factors and early predictors. During routine assessment of a child, it is advisable to screen for dyslexia by obtaining a comprehensive history of speech and language development, any early difficulties with naming (letters, objects or colours) and nursery rhymes. It is also important to let the child do some free writing and note spelling errors. Three essential features of dyslexia are inaccurate reading (distortions, omissions and substitution of words or parts of words), poor spelling with inaccurate letter orientation and slow, laboured reading[28]. After the initial screening, comprehensive assessment can be done using standard tests such as single-word reading tests, spelling tests and fluency tests[28]. For diagnosis of dyslexia the severity of reading difficulty has to be significant and persistent. It is also important to exclude other differential diagnoses of reading difficulties such as organic conditions (visual and hearing problems, brain pathologies), intellectual impairment and deprivation (low socio-economic background and poor stimulation).

Management principles of dyslexia

According to the "Multi-level model of Valatine 1989", dyslexia can be managed at four levels. They are managing biological risk factors (primary causes), partial performance deficits (secondary causes), reading and writing failures (primary symptoms) and emotional and behavioural disorders (secondary symptoms)[28].

The current Sri Lankan situation

In Sri Lanka, minimum attention is paid to specific learning disorders like dyslexia by both health and education sectors. Limited awareness of stakeholders results in very late identification and

wider 'dyslexia paradox'. Limited availability of trained staff in the school system results in poor support even after identification. So far, only very few studies have been done on dyslexia. A study to assess the knowledge of teachers on dyslexia showed that only special education teachers had training on dyslexia. In the same study most of the other primary school teachers had heard about dyslexia, but with lack of clarity as to what it was[35]. Epidemiological studies have not been done to assess its incidence or prevalence. There is no doubt that the individual, societal and economic burden of dyslexia in Sri Lanka is not given sufficient attention and even the tip of the iceberg is not visualized.

In our setting dyslexia is very much under-diagnosed. Frequently. it is an incidental finding at Child and Youth Mental Health Services (CYMHS). Many children are referred to CYMHS by school teachers due to poor school performance at the end of year 3 before they start getting prepared for the year 5 Scholarship examination. Other main presentations are depressive disorder, anxiety disorder, school refusal and multiple unexplained somatic symptoms.

The following two cases demonstrate some ways in which dyslexics may present, *albeit* rather late.

Case 1

A 10 year old girl from a well-educated family, getting prepared for grade 5 scholarship examination, was referred to the Child Psychiatry Unit from the paediatric ward after presenting with short attacks of loss of awareness about the surroundings. All possible organic causes for epilepsy were excluded. On assessment, she presented with a normal intelligence level with very poor school performance. She was diagnosed with a specific learning disorder. Poor school performance, anxiety and stress related to upcoming scholarship examination and the high expectations of the family were identified as aetiological factors for her presentation.

Case 2

A 13-year-old girl presented after a paracetamol overdose. On assessment, she was diagnosed with severe depression. Harassment and bullying at school by teachers due to poor school performance was the main precipitating factors for her depression. On assessment, she presented with a normal intelligence level and clinical features of dyslexia.

Areas to focus

It is vital to carry out research on different aspects of dyslexia in Sri Lanka. It is fundamental to formulate a screening tool which can be used by primary healthcare workers and preschool and primary school teachers. Translating and validating the diagnostic tools in Sinhala and Tamil is also a requirement. As early identification is the most important area, increasing awareness among primary healthcare workers such as public health midwives, public health inspectors and medical officers of health is an important area to be considered. They can be trained to educate parents about home literacy environment and identifying early warning signs and risk factors. Sri Lanka currently has an advanced maternal and child health programme. It can be augmented by integrating dyslexia warning signs to this programme. Education sector should focus on training more special education teachers and giving special training to preschool and primary school teachers. Special education programme should be integrated to mainstream education. Individuals with dyslexia should be given an individual education programme depending on their strengths and difficulties.

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