Enabling occupation through facilitating the diagnosis of Developmental Coordination Disorder

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Abstract

Background. The largest proportion of children seen within school-based occupational therapy is referred for handwriting difficulties. Many of these children have Developmental Coordination Disorder (DCD), a disorder that often goes undiagnosed, making if difficult for children, parents, and teachers to access resources. **Purpose.** The purpose of this article is to outline the important role of occupational therapists in recognizing and facilitating the diagnosis of DCD. **Key Issues.** In this paper, a case is made for an expansion of the role of school-based occupational therapists in facilitating diagnosis for children with DCD. Through a review of the literature, we establish the importance of a diagnosis for children and families and critically reflect on issues that may make therapists reluctant to become involved in facilitating this diagnosis. **Implications.** Occupational therapists working in schools are able to recognize children with DCD, an important first step in accessing key resources useful to improve occupational performance and quality of life.

Résumé

Description. La plus grande proportion des enfants recevant des services d'ergothérapie en milieu scolaire ont été aiguillés vers ces services en raison de difficultés à l'écriture. Un grand nombre de ces enfants sont atteints d'un trouble du développement de la coordination (TDC), un trouble qui échappe souvent au diagnostic du médecin ou d'autres intervenants; par conséquent, les enfants atteints d'un TDC, leurs parents et leurs enseignants ont souvent de la difficulté à avoir accès à des ressources. **But.** Le but de cet article est de décrire le rôle important que les ergothérapeutes peuvent jouer en reconnaissant et en facilitant le diagnostic d'un TDC. **Questions clés.** Dans cet article, les auteurs établissent le bien-fondé d'élargir le rôle des ergothérapeutes en milieu scolaire afin de favoriser le diagnostic des TDC. Au moyen d'une recension des écrits, les auteurs ont établi qu'il était important pour les enfants et les familles d'avoir un diagnostic et ils examinent de manière critique des questions pouvant rendre les ergothérapeutes hésitants face à leur participation à l'établissement de ce diagnostic. **Conséquences.** Les ergothérapeutes travaillant en milieu scolaire sont aptes à reconnaître les enfants atteints d'un TDC; il s'agit d'une première étape importante pour que l'enfant ait accès à des ressources clés en vue d'améliorer son rendement et sa qualité de vie.

Chools are a popular work setting for Canadian occupational therapists. Over 10% of members of the Canadian Association of Occupational Therapists report that they provide school-based occupational therapy services (von Zweck, 2006). Estimates vary, but the literature shows that handwriting difficulties are the most frequently cited reason for school-based occupational therapy referral. Studies have reported that up to 90% of referrals are for this particular problem (Feder, Majnemer, & Synnes, 2000; Hammerschmidt & Sudsawad, 2004). Occupational therapists often provide relatively focused handwriting assessment and intervention with these children (Case-Smith, 2002). In this paper, we argue that a significant number of children

who initially present with handwriting difficulties actually have Developmental Coordination Disorder (DCD) and that there are compelling reasons to ensure that this disorder is identified and diagnosed. Occupational therapists can play a critical role in this process.

Handwriting is a complex motor skill. In most school-work, handwriting problems impair a child's ability to copy assignments, take tests and produce written communication. Occupational therapists are recognized as playing a crucial role in assessing problems in handwriting and helping students and teachers identify and integrate solutions (Freeman, MacKinnon, & Miller, 2004). However, for children with DCD, handwriting may only be the tip of the iceberg in terms

of occupational performance problems. Missiuna and colleagues recently determined, in one urban area, that a majority of children who were referred to occupational therapy for handwriting problems met the diagnostic criteria for DCD (Missiuna, Pollock, Russell, & Law, 2005), a health condition that can affect all areas of occupational performance.

What is DCD?

DCD is a developmental disorder that is present from birth but typically becomes much more apparent once a child begins formal schooling (Cousins & Smyth, 2005). The diagnostic criteria for DCD, adapted from the *Diagnostic and Statistical Manual* (DSM) of the American Psychiatric Association (2000), are outlined in Table 1.

Not all children with DCD display the same motor difficulties. Certain aspects of the disorder may affect some children more severely, while other children have a more generalized impairment (Polatajko & Cantin, 2006; Visser, 2003). However, the difficulties described in Table 1 tend to consistently affect new motor learning and the performance of complex motor tasks. While children with DCD may improve specific tasks such as handwriting with instruction and practice, they are likely to continue to experience problems at school in many other areas of occupational performance. For example, children with DCD also demonstrate significant difficulty with self-care tasks (e.g., dressing, using utensils, toileting); academic tasks (e.g., copying, organizing seatwork, gym class); leisure activities (e.g., sports, playground activities); or a combination of the above (Miller, Missiuna, Macnab, Malloy-Miller, & Polajko, 2001). Difficulties in any of these areas can negatively affect the child's social integration and developing sense of self-concept (Skinner & Piek, 2001).

TABLE 1
Diagnostic criteria for Developmental Coordination Disorder

- A. Performance in daily activities that require motor coordination is substantially below that expected, given the person's chronolog ical age and measured int elligence. This may be manifested by:
 - marked delays in achieving motor milestones (e.g., walking, crawling, sitting)
 - dropping things
 - clumsiness
 - poor performance in sports
 - · poor handwriting.
- B. The disturbance in Criterion A significantly interferes with academic achievement or activities of daily living.
- C. The disturbance is not due to another general medical condition (e.g., cerebral palsy, hemiplegia, or muscular dystrophy) and does not meet criteria for a Pervasive Developmental Disorder.
- D. If mental retardation is present, the motor difficulties are in excess of those usually associated with it.

Although some estimates of the prevalence of DCD range from 5 to 15% of the primary school population (Wilson, 2005), the widely accepted rate is 5 to 6% or approximately 1 in 20 children (American Psychiatric Association, 2000). Given these rates, there is likely to be at least one child with DCD in every classroom. However, remarkably few children ever receive this diagnosis. Lack of awareness of the disorder among physicians and psychologists, the professionals who are most likely to make the diagnosis, may be a large factor in this discrepancy (Missiuna, Gaines, & Soucie, 2006). For example, a 2004 survey of 750 physicians in a large urban centre in Canada showed that 91% of the 191 respondents stated that they had never heard of DCD. Only 0.5% affirmed that they felt capable of making the diagnosis (Gaines, Missiuna, Egan, & McLean, 2006).

Physicians may lack awareness of DCD because the diagnosis is a relatively recent addition to the DSM of the American Psychiatric Association, having been added to DSM-IIIR in 1989. However, the disorder is not new. The scientific community has acknowledged the existence of a large group of children who have movement skill difficulties that are not due to any general medical condition for decades (Losse et al., 1991). Many titles and labels have been given to these otherwise typically-developing children who experience difficulties performing everyday motor skills (Polatajko, Fox, & Missiuna, 1995). Historically children have been described as clumsy (Walton, Ellis, & Court, 1962), physically awkward (Wall, McClements, Bouffard, Findlay, & Taylor, 1985), as having perceptual motor dysfunction (Laszlo, Bairstow, Bartrip, & Rolfe, 1988), developmental dyspraxia (Cermak, 1985) or sensory integrative dysfunction (Ayres, 1971). These terms do not distinguish the specific difficulties experienced by the children in any meaningful way (Missiuna & Polatajko, 1995). As a result, an international consensus meeting was held in 1994 to debate the usage of different terms and to streamline research in this field: researchers and clinicians from around the world agreed to accept the diagnostic term Developmental Coordination Disorder as an umbrella term to describe these children (Polatajko et al., 1995). Today, the term DCD is far more widely accepted. Published literature concerning the issues of these children has increased dramatically in the last decade (Magalhaes, Missiuna, & Wong, 2006).

It is important to appreciate that DCD is often present with other childhood onset disorders (Wilson, 2005), for example, attention deficit hyperactivity disorder (ADHD)(Piek & Dyck, 2004), dyslexia (Iversen, Berg, Ellertsen, & Tonnessen, 2005), speech/language impairment (Gaines & Missiuna, 2007; Webster, Majnemer, Platt, & Shevell, 2005) or a combination of these disorders (Kooistra, Crawford, Dewey, Cantell, & Kaplan, 2005). Comorbidity is so common that some researchers have declared that the child with "pure" DCD is the exception rather than the rule (Visser, 2003).

Why should DCD be identified and diagnosed?

Children with DCD need a combination of services to provide a holistic approach to their diverse movement difficulties (Kirby, 2005). Evidence suggests that delaying identification, and thereby intervention, for their movement difficulties can lead to negative secondary consequences (Hamilton, 2002). The difficulties that children with DCD experience are usually evident to their parents at a very early age (Missiuna, Moll, Law, King, & King, 2006) and are also visible to their peers (Cairney, Hay, Faught, Mandigo, & Flouris, 2005). Over time, parents notice an evolution in the difficulties that are of greatest concern. A progression has been described from motor and play concerns in the early years, to self-care, academic and peer-related problems in middle childhood, to more difficult challenges in later childhood related to decreased self-esteem and emotional health issues (Missiuna, Moll, King, King, & Law, 2007). Despite awareness that something is amiss, parents can have great difficulty obtaining an appropriate diagnosis. As Missiuna, Moll, Law et al. illustrated, parents of school aged children with DCD often consult with ten or more health and educational professionals in search of an explanation for their children's motor difficulties. When families finally receive a diagnosis, they are relieved. Parents seek an understanding and an answer to their questions of why their child is having these coordination difficulties (Ahern, 2000). They seek closure and with this improved understanding they can move onto advocating for their child, finding early interventions that will promote adaptation and may prevent secondary consequences (Missiuna, Gaines, Soucie & McLean, 2006).

Receipt of a diagnosis can also be helpful within the educational system (Missiuna, Moll, King, King, & Law, 2006). Although the diagnosis of DCD may not be recognized as a reason for the provision of special services, a medical diagnosis may give added weight to a parents' request for an Individualized Education Plan that recognizes their children's strengths and accommodates their needs. After learning of the diagnosis, teachers may view children more positively and recognize the discrepancy between their performance on written evaluations and their actual potential (Missiuna, Moll, King et al., 2006). A diagnosis can also help parents and teachers access targeted materials to help children with DCD overcome occupational performance problems, such as the CanChild resource materials (www.canchild.ca). Parents report that teachers find the suggestions in the article. They're bright but can't write (Missiuna, Rivard, & Pollock, 2004) to be constructive for both task and environmental modifications.

What is the role of occupational therapy in facilitating accurate diagnosis?

School aged children who exhibit fine and gross motor difficulties are referred regularly to occupational therapy for assessment and intervention (Dunford, Street, O'Connell, Kelly, & Sibert, 2004; Green et al., 2005). In addition to the usual handwriting problems, these children are often disorganized, have poor judgment of force and distance, have low tone, slump over the school desk, and have an awkward pencil grip, poor manipulative skills, and many other signs of inadequate motor control and coordination (Henderson, 1992; Miller et al., 2001; Wright & Sugden, 1996). As part of their work observing children in the classroom, school-based occupational therapists are in an excellent position to identify children who may have DCD.

If an occupational therapist is seeing a child with a hand-writing problem and becomes aware of signs or symptoms indicating the potential presence of DCD, it is his or her responsibility to make the parent aware that a thorough investigation is recommended and to suggest a referral to an appropriate profession for a diagnosis (College of Occupational Therapists of Ontario, 1996). With family consent, the child's physician may benefit from hearing directly from the occupational therapist regarding his or her observations and concerns.

What is the contribution of occupational therapy to a diagnosis of DCD?

The role of the physician in diagnosing DCD is clear. DCD is a diagnosis by exclusion so a physician needs to rule out other possible explanations for the child's coordination difficulties (e.g., neurofibromatosis, tumors, muscular dystrophy) (American Psychiatric Association, 2000; Hamilton, 2002). The absence of other medical conditions that would explain coordination problems is only one of 4 diagnostic criteria. It may be difficult for a physician to determine whether children meet some of the other criteria required for a diagnosis of DCD (see Table 1).

Results of a motor assessment are required to determine whether criterion A is evident (i.e., the presence of significant motor impairment and motor skill delay). Such an assessment is well within the scope of practice of an occupational therapist. Although there is no gold standard for identifying DCD-related motor difficulties (Missiuna, Rivard, & Bartlett, 2006; Crawford, Wilson, & Dewey, 2001), the Movement Assessment Battery for Children (M-ABC) (Henderson & Sugden, 1992) and the Bruininks-Oseretsky Test of Motor Proficiency (BOT) (Bruininks & Bruininks, 2006) are two normative measures often used by occupational therapists that can establish the extent of a child's motor delay. They provide different types of information: the BOT measures motor skill development while the M-ABC

provides an indication of the severity of the child's motor impairment. Clinical observations made during the administration of these standardized measures are extremely important in assessing children with DCD and may contribute more valuable information than the quantitative scores (Missiuna & Pollock, 1995).

Occupational therapists are also extremely well-positioned to provide information about criterion B, which addresses the impact of motor impairment on activities of daily living and/or academic activities (Dunford et al., 2005). The Canadian Occupational Performance Measure (Law et al., 1998), the Perceived Efficacy and Goal Setting (PEGS) System (Missiuna, Pollock, & Law, 2004) and the Children's Occupational Self-Assessment measure (Keller, Kafkes, Basu, Federico, & Kielhofner, 2005) are examples of tools that can be used to guide a clinical interview and gather information from different respondents about the impact of children's motor impairment on daily activities. Children with DCD often identify quite different areas of difficulty than parents and teachers, and therefore the perspective of the child should not be overlooked (Dunford et al., 2005). The School Function Assessment (Coster, Deeney, Haltiwanger, & Haley, 1998) or the Miller Function and Participation Scales (Miller, 2006) may provide useful information about academic impact and the accommodations and adaptations that are already being made within the school setting. Tools such as the Children's Assessment of Participation and Enjoyment (King, et al., 2004) may be useful if a therapist wishes more information about the diversity of activities in which a child participates outside of school.

Parents have an important role in providing information about a child's abilities at home, which may help confirm or refute a DCD diagnosis. With conditions such as DCD, where difficulties can range from subtle to obviously impaired, the occupational therapist should conduct a semi-structured interview and listen for parental comments about the quality and efficiency of the child's every day task performance at home, school and play. During a study of 116 children with motor impairment referred to an occupational therapist, the authors developed a parent interview guide (see Table 2) focused on concerns that are well within the scope of occupational therapy practice and that affirm the impact of the motor difficulties on occupational performance.

Why might occupational therapists hesitate to become involved in a diagnostic process?

While occupational therapists may be extremely well-positioned to identify children who have DCD, and to provide essential information to assist a physician in the formation of an accurate diagnosis, they may be reluctant to become involved in this way for a number of reasons. In this section, we explore potential barriers expressed by occupational ther-

apists and physicians who have participated in previous studies (e.g., Gaines et al., 2006; Missiuna, Pollock, Russell, & Law, 2005) and provide evidence-based counterarguments.

Limited personal knowledge of DCD

Despite the fact that DCD is widely discussed in the literature, it takes time to translate this knowledge into clinical practice. However, lack of knowledge is one of the easier barriers to overcome. Excellent articles are now available that summarize literature about children with DCD from a clinical perspective (e.g., Polatajko & Cantin, 2006; Wilson, 2005). Books on DCD such as the one edited by Cermak and Larkin (2002) cover an array of topics in an evidence-based manner. The internet offers free access to educational resources, for example, materials posted by CanChild and online, peerreviewed articles (e.g., Missiuna, Gaines & Soucie, 2006) that include video clips. Many options are available through which therapists can increase their knowledge about this population of children, even for therapists in more remote locations.

Reluctance to engage in a process that leads to the child receiving a label

The negative consequences of labeling a child with DCD are far outweighed by the benefits of obtaining access to information and resources that help children and their families to self-manage this chronic disorder. Regardless of the stage and presentation of each child, the negative impact of this disorder is debilitating not only for the child but also for the child's family (Missiuna, Moll, Law et al., 2006). To deal with this disorder and address the negative secondary consequences of having DCD, the first crucial step is to receive a diagnosis (Missiuna, Moll, Law et al., 2006; Rodger & Mandich, 2005). Without a diagnosis, children, families, and others around them live in a kind of limbo. Parents do not easily understand the difficulties experienced by their child, nor do they have access to services that will help them manage and alleviate some of their concerns (Hamilton, 2002). To complicate the picture, the difficulties experienced by the child with DCD are not neatly packaged or contained within the motor control realm and may become more complex over time. A label that leads to information provides important guidance about the issues that may subsequently arise and how to prevent or ameliorate them.

A closely related concern that physicians have expressed is a reluctance to introduce the possibility of another diagnosis, if a child already has one. Failure to identify the comorbidity of DCD may cause individuals who are involved with children to miss the extent and impact of their motor problems on everyday tasks (Missiuna, Moll, King et al., 2006). The American Psychiatric Association has highlighted the importance of acknowledging the child's motor challenges, in addition to other diagnoses, by stating in their diagnostic cri-

TABLE 2

Clinical interview guidelines

What types of activities are difficult for your child?

Probe for information about:

Self-care

- Dressing (clothing on backwards, difficulty or slow to complete fasteners/buttons/socks/shoelaces)
- Eating (spills food, poor use of utensils, difficulty pouring, preference for finger feeding)
- Hygiene issues (tooth brushing, shampooing)
- Toileting (accidents, constipation, difficulty wiping after bowel movements)

School

- dislike/avoidance of motor-based activities
- gap between what the child can say and writing ability
- difficulties with fine motor activities(printing/ handwriting, colouring, cutting, written language)
- homework resistance or excessive amount of time spent
- failure to complete work at school, disorganized approach
- social isolation, being teased or bullied

Leisure

- avoidance of sports, particularly ball games and team sports, trying and then quitting, fear of getting injured
- trouble learning to ride a bike,
- preference for sedentary activities (TV, video games, computer),
- frustration, social isolation, lack of friends
- difficulty initiating and maintaining play

Are these difficulties that you have noticed for a while or has anything changed? Probe for

- timing of onset of difficulties (usually more apparent once school begins)
- accidents, illnesses or emotional incidents

Has there been a time when you have tried to teach your child to do something and it has taken longer than you think it should?

Probe for

- type of tasks were difficult to teach and for child to grasp
- comparisons with the child's siblings or other children in their social group.

Listen for continuing dependence on parents, difficulties with organization, excessive time and frustration with these tasks

Listen for conflicts over homework, avoidance behaviours (particularly written work and task completion)

Listen for pattern of taking a longer time to learn motor skills, selective participation, parents having to initiate contact for friendships

Listen for progressive occurrence of difficulties rather than a sudden change; realization of difficulties escalation with new motor skill demands

Listen for comments expressing an ability for child to master motor skills that are repetitive but only with much practice and low quality of final performance; discrete tasks very difficult to teach; parent giving up trying to teach a task, preferring to do tasks for the child.

teria for DCD, "if criteria for both disorders are met, both diagnoses can be given" (American Psychiatric Association, 2000, p. 57).

A belief that it is possible to make the underlying motor impairment go away

Longitudinal studies suggest that the coordination difficulties experienced by children with DCD do not simply disappear (Cantell, Smyth, & Ahonen, 1994; Cantell, Smyth, & Ahonen, 2003; Losse et al., 1991). Perhaps of more concern is the evidence that secondary consequences of DCD emerge and worsen over time. Children with DCD frequently develop

secondary behavioural difficulties (Cummins, Piek, & Dyck, 2005;) and exhibit emotional and social problems (Heath, Toste, & Missiuna, 2005; Skinner & Piek, 2001). Poor self-efficacy has been cited as the reason that children with DCD are reluctant to participate in typical childhood activities (Cairney, Hay, Faught, Wade et al., 2005; Cairney, Hay, Wade, Faught, & Flouris, 2006). This reduced level of physical activity makes them more prone to being overweight or obese (Cairney, Hay, Faught, & Hawes, 2005). In this vicious circle, withdrawal from physical activity results in fewer opportunities for children to socialize and make friends. Children with DCD have been shown to be poor at socializing with their

peers (Cummins et al., 2005; Kanioglou, Tsorbatzoudis, & Barkoukis, 2005), to have reduced social acceptance (Heath et al., 2005; Watkinson et al., 2001) and to be at increased risk of victimization or bullying (Piek, Barrett, Allen, Jones, & Louise, 2005). Anxiety and depression often emerge by late childhood, possibly as a result of the well-established social isolation and low self-worth (Piek, Dworcan, Barrett, & Coleman, 2000). Children with DCD carry their difficulties into their adolescent years, where self-perceptions of scholastic and athletic competence remain lower than typically developing children and may lead to a shorter school career (Cantell et al., 2003). Recently evidence has surfaced that the motor difficulties experienced in childhood are retained into adulthood and continue to have a limiting effect on life choices such as not being able to drive a car (Cousins & Smyth, 2003). Although DCD does not go away, early recognition of the challenges and frustrations that children with DCD experience, increases the likelihood that some of these secondary physical and mental health consequences can be prevented.

Fear about overstepping professional boundaries

Occupational therapists have expressed concern that becoming involved in the process of diagnosis is going beyond their scope of practice. In Ontario, for example, communication of a diagnosis is a controlled act that can only be carried out by physicians, dentists, psychologists, chiropractors, optometrists, and podiatrists (College of Occupational Therapists of Ontario, 1996). However, therapists have an ethical responsibility to assist families to obtain an appropriate diagnostic work-up, particularly if the presence of a disorder is strongly suspected and the disorder could be effectively managed. In addition to discussing observations with a family, the occupational therapist might include recommendations in a report such as:

Matthew's challenges suggest that he may fit the diagnostic criteria for Developmental Coordination Disorder (DCD). The profession of occupational therapy does not diagnose medical conditions; therefore, referral to a physician or psychologist is recommended for further investigation.

During the assessment, Heather displayed many of the characteristics shown by children with Developmental Coordination Disorder. A visit to your family doctor is important so that he/she can follow-up on these issues.

Concern that the physician may not know how to diagnose DCD

Numerous studies have shown that many physicians have never heard of DCD and do not know how to diagnosis it (Dunford et al., 2004; Gaines et al., 2006; Kirby, Davies, & Bryant, 2005). Sending the physician (with parental consent)

a clear, succinct report that outlines the findings of the occupational therapy assessment and requests that the physician consider the possibility of DCD, is a great idea but may be insufficient. In order to advocate on behalf of the child, the occupational therapist may need to become familiar with educational materials that have been developed for primary care physicians and paediatricians to teach them about DCD and the diagnostic process for the disorder. Articles such as the ones by Hamilton (2002) and by Missiuna, Gaines & Soucie (2006) teach screening techniques, provide questionnaires, and show video clips from an office setting of a child with DCD and a typically-developing child. A free website has been designed for physicians, not only to share evidence about DCD, but to give them access to educational materials for their patients (www.dcdpack.ca).

Due to the diverse spectrum of difficulties (Visser, 2003), children with DCD may be brought to the attention of any number of other professionals including physical therapists, special educators, teachers, physical educators, speech/ language pathologists, psychologists, paediatricians, neurologists and family physicians (Green et al., 2005). At present, these professionals demonstrate differing levels of understanding of DCD (Dunford et al., 2004; Kirby et al., 2005). As DCD is increasingly recognized, health service providers are showing interest in publishing articles in their practice journals that provide information to help them recognize these children (Missiuna, Gaines, & Pollock, 2002; Missiuna, Rivard, & Bartlett, 2003). Speech/language pathologists, for example, have been particularly receptive to education about children with DCD. Research has demonstrated repeatedly that from 40% to 90% of preschool children with developmental speech/language difficulties have comorbid motor problems (Gaines & Missiuna, 2007; Hill, 2001; Webster et al., 2005). Occupational therapists can work with and educate their allied health colleagues to potentially identify children with DCD at younger ages. Short, evidence-based flyers outlining the role of each of these health professionals in recognizing DCD are available on the CanChild website (www.canchild.ca).

In conclusion, while occupational therapists have expressed concern about having an increased role in facilitating diagnosis of children with DCD, there is evidence to substantiate their involvement.

Conclusion

We believe that occupational therapists are well placed to recognize DCD and facilitate a diagnosis of this common childhood developmental condition. The scope of practice of occupational therapy includes the identification of occupational performance issues in self-care, school, and leisure activities and the assessment of performance components that are contributing to these problems. To avoid the debilitating effects of DCD, and to help families understand and advocate for their child, diagnosis needs to occur. Occupational therapists can actively and positively participate in this process to advance the early recognition of children with DCD. Occupational therapists have a critical role to play in providing assessment information that will assist the physician to arrive at an accurate diagnosis and that may improve access to services and education that supports children with DCD and their families.

Footnote

¹ This website was designed by the authors as part of a project funded by the Ontario Ministry of Health and Long Term Care. It is currently available to health professionals at no cost (username: dcdpack; password: dcdchild).

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