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Investigating quality of life and self-stigma in Hong Kong children with specific learning disabilities



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ABSTRACT

an academics-focused culture.

Background: Children with specific learning disabilities (SpLD) are likely to develop self-stigma and have a poor quality of life (QoL) because of their poor academic performance. Although both self-stigma and poor QoL issues are likely to be found in low academic achievers without SpLD, children with SpLD have worse situation because their diagnosis of SpLD suggests that their learning struggles are biological and permanent. Specifically, students' perception of own capabilities may be affected more by the diagnosis of SpLD than their own actual performance. Aims: We examined the self-stigma and QoL of children with SpLD in Hong Kong, a region with

Methods and procedures: Children with SpLD (n = 49, $M_{\rm age} \pm {\rm SD} = 9.55 \pm 1.21$; SpLD group) and typically developing children (n = 32, $M_{\rm age} \pm {\rm SD} = 9.81 \pm 1.40$; TD group) completed a Kid-KINDL to measure QoL and a Modified Self-Stigma Scale to measure self-stigma. All parents completed a parallel Kid-KINDL to measure QoL of their children.

Outcomes and results: Compared with the TD group, the SpLD group had a higher level of self-stigma (p=0.027) and lower QoL (child-reported Kid-KINDL: p=0.001; parent-reported Kid-KINDL: p<0.001).

Conclusions and implications: In the academics-focused environment in Hong Kong, SpLD was associated with impaired QoL and higher self-stigma. Treatments targeting the learning process of children with SpLD may be designed to overcome self-stigma and to improve QoL. In addition, the program may involve parents of the children with SpLD or other people (e.g., the peer of the children with SpLD) for improving their understanding and perceptions of SpLD.

What this paper adds

Other studies have reported that children with specific learning disabilities (SpLD) tend to have impaired emotional well-being, low self-esteem, and poor relationships with family and friends. In addition, children with SpLD are often stigmatized by their parents, educators, and peers. Being the targets of stigma might increase their self-stigma, and subsequently reduce their motivation to learn. However, there is scant research that provides information regarding self-stigma and quality of life (QoL) in children with SpLD from Asian cultures, especially the culture that have a high focus on academic excellence. This work provides information about the QoL and levels of self-stigma in a sample of 8–12-year-old Hong Kong children with SpLD. Children with SpLD reported

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significantly higher levels of self-stigma and significantly lower levels of QoL in physical well-being, school functioning, and friendships than did their counterparts without SpLD. Moreover, self-stigma was significantly correlated with child-rated QoL but not with parent-rated QoL in the SpLD group. Our findings indicate that children with SpLD have a lower QoL and a higher level of self-stigma than do children without SpLD. Hong Kong and other areas with highly competitive academics-oriented cultures should not neglect the QoL and self-stigma problems of children with SpLD. They need to develop proactive interventions that overcome self-stigma and improve QoL and that involve children with SpLD and their parents.

1. Introduction

A specific learning disability (SpLD) has been defined as a disorder that manifests "as significant difficulties in the acquisition and use of listening, speaking, reading, writing or mathematical abilities, despite access to conventional teaching" (The Hong Kong Society of Child Neurology and Developmental Paediatrics, 2008; p. 23). The DSM-5 diagnostic criteria for SpLD are "persistent and impairing difficulties with learning foundational academic skills in reading, writing, and/or math" (American Psychiatric Association, 2013). Such learning-related problems should not be attributed to identifiable disabilities, such as emotional distress and disabilities in visual skills, hearing, motor skills, or intelligence (Flanagan & Alfonso, 2010). Children with SpLD might have poor reading, spelling, or math skills, which, in turn, might induce negative attitudes in some teachers, and might later manifest as biased expectations of students (Hornstra, Denessen, Bakker, van den Bergh, & Voeten, 2010). Children with SpLD might internalize these prejudices and develop low self-esteem over time (Vogel, Bitman, Hammer & Wade, 2013), which might then affect their well-being. In other words, SpLD is about more than getting poor grades in school. We need to explore and recognize the by-product of their difficulties, particularly how it affects their quality of life (QoL) and self-stigma. Educators and healthcare providers might then be better prepared to provide care and assistance to vulnerable children.

Some researchers suggested that QoL could be a good indicator for understanding both mental and physical well-being when someone considers the cultural and social context when rating his/her own condition (Ou, Su, Luh, & Lin, 2016). In view of it, QoL can be used as an indicator for measuring an individual's well-being in healthcare research (Colver, 2008) across various environments, including the context of schools (Colver, 2008; Lin, Su, & Ma, 2012; Ravens-Sieberer et al., 2006). Based on the definition of QoL and the environment of a child, the QoL constructs include physical, psychological (emotion and self-esteem), social (friend and family), and environmental (school) domains. QoL problems of children with SpLD have been raised. Specifically, children with SpLD tend to have impaired emotional well-being, low self-esteem, and poor relationships with family and friends, which equate to their jeopardized overall health (Ginieri-Coccossis et al., 2013; Karande, Bhosrekar, Kulkarni & Thakker, 2009; Karande & Venkataraman, 2012). However, related investigations were focused primarily on populations outside Hong Kong (Karande, 2014; Karande et al., 2009; Karande & Venkataraman, 2012; Northway & Jenkins, 2003). Knowledge gaps about the QoL of children with SpLD, especially in Asian countries, remain and should be filled in.

In addition to QoL, self-stigma is an important concern for children with SpLD because of the unpleasantness and emotional pain of being laughed at by peers or rebuked by parents. Self-stigma is defined as a three-step process that includes legitimizing negative stereotypes and prejudiced attitudes, endorsing the stereotypes and attitudes, and subsequently experiencing negative consequences such as low motivation and low self-esteem (Corrigan, Watson & Barr, 2006). Students with SpLD are regarded as being less attractive, less successful, and less emotionally stable than are students without SpLD (Lisle, 2011). Based on the labeling theory, others' perceptions and legitimizing stratification of a certain population (e.g., children with SpLD are less attractive than those without SpLD) generate the stigma (Mehan, Hertweck, & Meihls, 1986). Consequently, the labeled population might perceive themselves and perform in accordance with others' perceptions (Scheff, 1966). Children with SpLD tend to believe, endorse, and internalize the biased perspectives of others, which is a factor for generating self-stigma (Goffman, 1963).

Shifrer (2013) found that teachers and parents tend to have low educational expectations of students with SpLD, and might even label these students as disabled. Shifrer (2013) also found that using learning disability labels for students is implicated in the lower educational expectations of students with SpLD because it induces them to develop self-stigma. Educators might not appreciate the effects of SpLD, and often judge students with SpLD as lazy (Lisle, 2011). Together with poorer academic performance compared with typically developing (TD) children (Smith & Nagle, 1995), children with SpLD easily perceive themselves as incompetent, and inferior to their peers (Grolnick & Ryan, 1990), which increases their risk of developing self-stigma. However, most studies of stigma associated with SpLD discuss adolescents and public stigma (Banerji & Dailey, 1995; Denhart, 2008; Grolnick & Ryan, 1990; Shifrer, 2016) but rarely discuss children and self-stigma (Shifrer, 2013). Hence, we suggest examining the self-stigma of children with SpLD to offer useful information to educators and healthcare providers about how self-stigma is developed and how to prevent it from occurring. Although low academic achievers without SpLD are also likely to be targets of biased perceptions and to generate self-stigma, we consider that their conditions are different from those of children with SpLD. Children with SpLD may experience extra stigma because the diagnosis of SpLD suggests that their learning struggles are biological and permanent.

We have further justifications to support our hypothesis that children with SpLD have higher level of self-stigma than those without SpLD. A study found that high academic achievers with SpLD did not have a higher academic self-efficacy, a psychological factor related to self-stigma, than low academic achiever without SpLD (Lackaye & Margalit, 2006). This implies that students' perception of own capabilities may be affected more by the diagnosis of SpLD than his/her own actual performance. In other words, if someone has SpLD and low academic achievement, his/her self-efficacy will be worse than someone has low academic performance only. In addition, most educators might have less knowledge of the characteristics of SpLD than other disabilities (e.g., intellectual disability), such condition may lead to a misunderstanding of the underlying causes of low academic performance in students with SpLD. Teachers' biased perception may easily induce self-stigma in SpLD students. Taken the two aforementioned issues together,

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