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Comparison of health-related quality of life between children with cerebral palsy and spina bifida

Sezen Tezcan^a, Tülay Tarsuslu Simsek^{b,*}^aSpecial Ilgim Special Education and Rehabilitation Center, Düzce, Turkey^bDokuz Eylül University School of Physical Therapy and Rehabilitation, Izmir, Turkey

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ABSTRACT

This study has two aims—the first is to compare the Health Related Quality of Life (HRQoL) between children with cerebral palsy (CP) and children with spina bifida (SB); the second is to investigate the relationship between HRQoL and age, sex, body mass index (BMI), level of ambulation, cooperation, family income and the mother's education level in both groups of children. The study included 96 children with CP and 70 children with SB (aged 5–18) who attended a physiotherapy and rehabilitation program at an institute of special training and rehabilitation. Socio-demographic information was obtained within the study. The Child Health Questionnaire (CHQ-PF50) was used to evaluate HRQoL. A significant difference was found in terms of age and BMI between children with CP and SB ($p < 0.05$). HRQoL was lower for children with CP. There was a significant difference between the two groups in terms of role/social limitations – emotional behavioral, behavior, global behavior, parental impact-emotional and parental impact-time ($p < 0.05$). A positive correlation was found between BMI and self-esteem in children with SB, unlike children with CP. The HRQoL of children with CP was lower than children with SB. The parameters of behavior and parental impact were particularly affected in the children with CP. Minimizing behavioral problems (which can improve with advancing age) of the children with CP and reducing parental impact are important for improving the HRQoL of both the child and parents. There is a need for further studies on this issue.

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1. Introduction

Cerebral palsy (CP) is caused by damage to the motor-control centers of the brain during pregnancy, during delivery and/or in the post-natal period. Cerebral palsy limits physical activities, and is non-progressive. It is described as a permanent disability in development of posture and movement (Bax, Goldstein, & Rosenbaum, 2005; Krageloh-Mann & Cans, 2009; Robaina-Castellanos, Riesgo-Rodriguez, & Robaina-Castellanos, 2007; Rosenbaum, Paneth, & Leviton, 2007). The incidence of CP in developed countries is between 1.5 and 2.5 per 1000 live births and is the most common cause of severe motor disability during childhood (Cans, Surman, & McManus, 2004; Drougia, Giapros, & Krallis, 2007). According to a study in Turkey, the incidence of CP was 4.4 in every 1000 live births (Serdaroğlu, Cansu, & Özkan, 2006).

Spina bifida (SB) is a structural defect that occurs in vertebra and medulla spinalis, and is caused by incomplete closing of the neural tube. It results in anomalies in skin, muscle, vertebra, meninges and neural tissue (Cameron & Monroe, 2007; Campbell, Vander Linden, & Palisano, 2007; Mitchell, Adzick, & Melchionne, 2004). It is the second clinical picture, following

* Corresponding author. Tel.: +90 2322778711.

E-mail address: tulay_tarsuslu@yahoo.com (T.T. Simsek).

CP, which causes disability in childhood (Campbell et al., 2007). The incidence of CP varies in different communities (Cameron & Monroe, 2007); for example, African countries have the lowest incidence, of 1 in 10,000. East Ireland and West Scotland have the highest incidence, with a rate of 1 in 80. The incidence of SB ranges between 3.7% and 18% in each of monozygotic twins (Campbell et al., 2007). The incidence of SB is higher in girls than boys (Mitchell et al., 2004). Studies conducted in Turkey concluded that the incidence of SB ranges from 3 to 5.8 per 1000 live births (Tunçbilek, Boduroğlu, & Alikaşifoğlu, 1999). More than 70% of SB cases can be prevented by folic acid reinforcement in the maternal period (Mitchell et al., 2004).

These two chronic conditions (SB and CP) affect the quality of life of children and their parents. Multiple symptoms and complications present a range of physical, intellectual, orthopedic, hearing, visual, and communication impairments, with a wide range of severity, and are likely to influence quality of life (QoL) (Majnemer, Shevell, & Rosenbaum, 2007; Okurowska-Zawada, Kułak, & Otapowicz, 2011; Steinbol, Irvine, & Cohrane, 1992). There has recently been an increase in the number of studies on these conditions (CP and SB) (Davis, Shelly, & Wates, 2010; McCullough, Parkes, & Kerr, 2011; Majnemer et al., 2007; Okurowska-Zawada et al., 2011; Peny-Dahlstrand, Ahlander, & Sundlhom, 2006), which concluded that motor impairment, pain, communication problems, intellectual impairment and seizures have significant negative effects on HRQoL and participation in daily activities, both of which incorporate elements of health and well-being (Fauconnier, Dickinson, & Beckung, 2009; McCullough et al., 2011; Tarsuslu Şimşek & Livanelioğlu, 2011). Studies on children with SB focused on the negative effect of mobility limitation, urinary incontinence and the level of lesions on HRQoL (Bier, Prince, & Tremont, 2005; Cornegé-Blokland, Jansen, & de Jong-de Vos van Steenwijk, 2011; Okurowska-Zawada et al., 2011).

There are numerous studies that examine HRQoL and the factors affecting it in children with CP and SB (Bier et al., 2005; Cornegé-Blokland et al., 2011; Fauconnier et al., 2009; Majnemer et al., 2007; McCullough et al., 2011). However, few studies have compared HRQoL of children with CP and SB. Our study has two aims: to compare HRQoL between children with CP and SB; and to investigate the relationship between age, sex, body mass index (BMI), level of ambulation, cooperation, family income and level of education of the mother in both groups of children.

2. Methods

The study included 96 children with CP and 70 children with SB (5–18 years old) life. Participants were already attending a physiotherapy and rehabilitation course. Inclusion criteria were: children diagnosed with CP and SB, aged 5–18 years old, attending a physiotherapy and rehabilitation program in an institute of special training and rehabilitation, access to the child's primary carer, voluntary participation in the study by both child and parent. Exclusion criteria were: children and parents declining to participate in the study, mothers with cognitive disabilities who were not able to complete self report questionnaires, non-access to the child's primary carer, children with any neurological problems in addition to CP and SB. We preferred parents who are closely responsible for the children. Information about the children was obtained from parents. We confirmed the diagnosis of CP and SB in each case.

The parents whose children were included in the study signed a consent paper in which the method and aim of the study was explained. The study was approved by the Ethics Committee of Clinical Research in Bolu (Ref. no. 2010/10). Clinical characteristics of the children with SB and CP and socio-demographic data and was collected by examining the age of the child, height, body weight, BMI, clinical type and degree of influence in children with CP, co-operation (communication ability), level of spinal cord lesion in children with SB, ambulation ability of the children with CP and SB, level of education and income of the parents in both groups of children. BMI was calculated as a percentile, and the subject was placed into one of four categories: (1) healthy weight (5–85th percentile); (2) overweight (85–95th percentile); (3) obese (greater than or equal to 95th percentile); and (4) underweight (less than the 5th percentile).

In children with CP and SB, who were not able to walk and stand, the weight measurements were taken while the child was held on her mothers' lap. After measuring the mother weight, the mother was instructed to stand on the scale with the child. Then, the mother's predetermined weight was subtracted from the second measurement and resultant weight was recorded as the child's weight.

2.1. Motor function

A physiotherapist evaluated the level of disability and ambulation ability of the children with CP using the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, & Walter, 2011). GMFCS is a classification system developed for children with chronic disabilities. It is based on activities that are initiated by the child, such as sitting, motion, and mobility. The motor abilities of children vary according to age, so functions were determined according to age groups: less than 2 years old, 2–4 years old, 4–6 years old, 6–12 years old. The scale was previously used only for children up to age 12, but the extended version can now be used for teens aged 12–18 (Jahnsen, Aamodt, & Rosenbaum, 2006). The GMFCS levels are described as follows: level I, walks without restriction; II, walks without assistive devices, limitations in walking outdoor; III, walks with assistive devices; IV, self-mobility with limitations, children are transported or use powered mobility; V, self-mobility is severely limited.

Ambulatory status in patients with SB was classified according to four levels: (1) independent ambulation with no assistive devices; (2) walking full-time using an assistive devices; (3) walking with an assistive device at home but uses a wheelchair in the community; and (4) uses a wheelchair full-time (Flanagan, Gorzkowski, & Altiok, 2011).

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