Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: A cross-sectional study

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\textbf{ABSTRACT}

\textbf{Objective:} To compare quality of life (QOL) according to ambulatory status and to investigate association with habitual physical activity (HPA) in children with cerebral palsy (CP) aged 5 years.

\textbf{Methods:} Fifty-eight participants were classified using Gross Motor Function Classification System (GMFCS) as level I = 33, II = 8, III = 6, IV = 3 and V = 8 and assessed for motor function using 66-item Gross Motor Function Measure (GMFM-66). Participants wore an ActiGraph\textsuperscript{®} triaxial accelerometer for 3 days to measure HPA. Parents completed the parent proxy Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child). Linear regression analyses were performed.

\textbf{Results:} Ambulant children with CP (GMFCS I–III) had better parent-reported QOL than non-ambulant children (GMFCS IV–V) in domains of feelings about functioning (mean difference (MD) = 20.0; 95% confidence interval (CI) = 11.7, 28.2), participation and physical health (MD = 14.5; 95%CI = 4.7, 24.4), and emotional well-being and self-esteem (MD = 12.5; 95%CI = 4.8, 20.1). HPA was not associated with QOL domains after controlling for motor function. GMFM scores accounted for 39% of variation for feelings about functioning domain (MD = 0.4; 95%CI = 0.2, 0.6).

\textbf{Conclusions:} In children with CP aged 5 years, HPA was not associated with parent-reported QOL. Gross motor function contributed to QOL domains of feelings about functioning.

\textbf{What this paper adds}

- Ambulant children with cerebral palsy had better parent-reported quality of life than non-ambulant children in domains of feelings about functioning, participation and physical health, and emotional well-being and self-esteem.
- Higher motor function is associated with better quality of life in domains of feelings about functioning.
- Habitual physical activity was not associated with parent-reported quality of life after controlling for motor function in children.

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with CP aged 5 years.

1. Introduction

Cerebral palsy (CP) is one of the most common physical disabilities in children with a prevalence of CP of 2 per 1000 live births (Oskoui, Coutinho, Dykeman, Jette, & Pringsheim, 2013). It is defined as a group of disorders of movement and posture caused by a lesion in the developing brain (Rosenbaum et al., 2007). The World Health Organization (WHO) defined QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 2001). Quality of life (QOL) is multidimensional and can be assessed using either generic or condition-specific measures (Gilson, Davis, Reddihough, Graham, & Waters, 2014). Generic QOL questionnaires such as the KIDSCREEN (Ravens-Sieberer et al., 2005), the Child Health Questionnaire (CHQ) (Landgraf, Abetz, & Ware, 1996) and the Pediatric Quality of Life Inventory (PedsQL 4.0) (Varni, Seid, & Kurtin, 2001) can be used across populations and allows comparison among a variety of patient populations. Generic questionnaires may not cover domains of importance to children with CP. The Cerebral Palsy Quality of Life questionnaire for children (CP QOL-Child) is a condition-specific measure developed to assess well-being for children with CP aged 4–12 years (Waters et al., 2013). It has the strongest evidence of measurement properties among condition-specific QOL measures for children with CP (Carlton et al., 2010).

Determinants of QOL in CP children with CP have been investigated in many studies (Arnaud et al., 2008; Bjornson et al., 2008; Dickinson et al., 2007; Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007; Pirpiris et al., 2006; Shelly et al., 2008). Functional ability, as classified by the Gross Motor Function Classification System (GMFCS), is one of the determinants associated with various QOL measures in physical, but not psychological, domains (Arnaud et al., 2008; Bjornson et al., 2008; Dickinson et al., 2007; Majnemer et al., 2007; Pirpiris et al., 2006; Shelly et al., 2008). The Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), a large population-based study of 818 children from seven European countries, reported that the GMFCS was significantly associated with both self-reported and parent-reported KIDSCREEN for domains of physical well-being and autonomy (Arnaud et al., 2008; Dickinson et al., 2007). In addition, the GMFCS was significantly associated with physical domains of the CHQ and the PedsQL4.0 (Bjornson et al., 2007; Majnemer et al., 2007; Pirpiris et al., 2006). The GMFCS has been shown to be significantly associated with all domains of the parent proxy CP QOL-Child except access to services (Shelly et al., 2008). The Gross Motor Function Measure (GMFM), a criterion-referenced motor function measure, had the strongest association with the CHQ and PedsQL4.0 compared to the child’s mastery motivation (Majnemer et al., 2007).

Habitual physical activity (HPA) has been defined as “any bodily movement produced by skeletal muscles which results energy expenditure in daily life” (Caspersen, Powell, & Christenson, 1985). Our previous study found that marginally-ambulant (GMFCS III) and non-ambulant (GMFCS IV–V) children with CP aged 4–5 years had significantly lower HPA and were less likely to meet the Australian Physical Activity Guidelines compared to independently-ambulant children with CP (GMFCS I–II) (Keawutan, Bell, Oftedal, Davies et al., 2017). In the past decade, interventions for children with CP have shifted from a focus on improved attainment of developmental milestones for motor skills to include improved HPA (Damiano, 2006; Rowland, Fragala-Pinkham, Miles, & O’Neil, 2015; Verschuren et al., 2007). Recently, physical activity guidelines for people with CP were launched to promote healthy lifestyles and prevent risk of cardiovascular and metabolic diseases (Verschuren, Peterson, Balemans, & Hurvitz, 2016). Studies in children with typical development indicated that HPA levels in early childhood were sustained until young adulthood (Jones, Hinkley, Okely, & Salmon, 2013; Telama et al., 2014). In children with typical development, there is strong evidence that HPA can improve physical health, including cardiorespiratory, cardiovascular, muscular fitness and bone health (U.S. Department of Health and Aging, 2008). In addition, moderate evidence has shown that HPA can improve mental health including self-esteem, and reduce depression and anxiety (Biddle & Asare, 2011; U.S. Department of Health and Aging, 2008). Regarding children with neurodevelopmental disabilities, systematic review reported that engaging in active physical leisure activities (for example bicycling, horse riding, and organized activities) was positively associated with better QOL (Dahan-Oliel, Shiakako-Thomas, & Majnemer, 2012). Exercise training can also improve health-related quality of life in children with CP aged 7–18 years (Verschuren et al., 2007). Previous studies reported that HPA levels in children with CP started to decline at the age of 5 years (Keawutan, Bell, Oftedal, Ware et al., 2017). To date there have been no studies examining the relationship between QOL specifically in young children with CP and levels of HPA. If they are correlated, increased HPA levels at young age would improve their QOL. The aim of this study was to use a condition-specific QOL measure for children with CP and objective physical activity measures to (i) compare parent-reported QOL among children with differing functional abilities, and (ii) examine relationships between HPA and parent-reported QOL in children with CP aged 5 years.

2. Methods

This cross-sectional study is a sub-study of two larger population-based cohort studies, the Queensland CP Child Study of Motor Function and Brain Development, trial registration: Australia and New Zealand Clinical Trials Register (ACTRN1261200169820) (Boyd et al., 2013) and the Queensland CP Child Study of Growth, Nutrition and Physical Activity, trial registration: ACTRN12611000616976 (Bell et al., 2010). Queensland children with CP born in 2007–2009 were eligible for inclusion. Children with progressive or neurodegenerative lesions were excluded. Participants were selected for this sub-study if data on the CP QOL-Child and HPA were available at 60 ± 1 months corrected age. Ethics were approved by the University of Queensland Medical Research Ethics Committee (2008002260) and regional hospitals across Queensland, Australia. Informed consent was obtained by all parents or legal guardians of participants.
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