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Research Paper

Quality of life in young adults with cerebral palsy

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Abstract

Background: Little is known about the quality of life (QOL) of young adults with cerebral palsy.

Objective/hypothesis: This cross-sectional analysis compares the QOL of a cohort of young Australian adults with CP with a cohort of able-bodied peers to explore the relationship between QOL and impairments, functioning, and social participation.

Methods: Young adults identified from the Victorian Cerebral Palsy Register were invited to complete a survey about QOL, gross motor function, independence in self-care, and social participation. QOL was assessed with the Quality of Life Instrument for Young Adults (YAQOL). A general population sample of young North American adults, who had completed the YAQOL was selected for comparison.

Results: Surveys and consent forms were completed by 335 young adults or their proxies, an overall participation rate of 63% of those located. The mean age of the study participants was 24.7 [s.d = 2.8] years; 51% were male and 49% female. Two hundred and seven (62%) of the 335 participants self-reported their QOL. When compared with the general population sample, self-reporting participants had similar QOL scores for the social relationship and environmental context domains ($p > 0.05$), while QOL scores were lower for the physical health, psychological well-being, and role function domains ($p < 0.001$). There was no association between psychological well-being and variables related to body structure and gross motor function in young adults with CP.

Conclusions: Contrary to the assumption that young adults with severe CP have low psychosocial well-being, it is apparent that these individuals can have good psychosocial well-being regardless of their disability.

Keywords: Quality of life; Young adults; Cerebral palsy; Well-being

Cerebral palsy (CP) is the most common physical disability in childhood.[1] Overall, 90% of individuals with CP are expected to grow into adulthood.[2] In 2007, it was estimated that 74% of Australians with CP were aged 20 years and over.[3] Much is known about outcomes in childhood but far less has been reported about outcomes in young adults, information that would be useful in helping families to plan their child's future needs and would also assist health providers in formulating short and long term goals. An outcome that is important to consider is quality of life (QOL). Quality of life (QOL), a subjective and multidimensional concept, is defined by the World Health Organisation 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.'[4]

The level of QOL reported by children with CP varies depending on the QOL instrument used. Studies using instruments that focus on health and function tend to find that the QOL of children with CP is lower than the QOL of their typically developing peers.[5–7] By contrast, studies that have used instruments focusing on subjective perceptions of life have demonstrated that, with the exception of physical well-being, QOL of children with CP is similar to their typically developing peers.[8,9] Although gross motor function has been associated with physical well-being,[8–10] it has not been shown to be associated with social or psychological well-being.[9,10]

Little is known about the QOL of adults with CP. Although a few studies have now been conducted in adults, only one study was population-based and thus

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representative of the entire CP population. Other studies included adults across a wide age range or a mix of different disabilities. For example, a large North American study of 3638 young people (16–27 years) with CP and other developmental disabilities demonstrated that 80% of the sample was satisfied with life in general.[11] Furthermore, a Japanese study on the subjective well-being of 81 adults with CP (26–51 years) found that adults whose physical health was poor, and those who were dependent in activities of daily living, reported lower well-being scores.[12] An additional finding was that well-being scores were lower for individuals aged in their early 40s than for those in their early 30s. A study of 199 adolescents and young adults with CP, which measured QOL using a utility QOL measure demonstrated that QOL scores for adolescents and young adults were similar.[13]

To our knowledge, the only population-based study of adults with CP was conducted in Norway.[14] Using the Life Satisfaction Scale,[15] results from this study demonstrated that more than half the participants were satisfied with their life as a whole, their ability to perform activities of daily living, their family life, and their contact with friends. One third felt satisfied with their work situation and less than one third was satisfied with their sexual life and partner relationships. Compared to the general population, adults with CP reported significantly lower satisfaction scores for life as a whole, sexual life, family life, ability to perform daily activities, leisure, and work.[14]

There have been no population-based studies that have focused specifically on the QOL of young adults with CP aged 20–30 years. Individuals in this age group are at a particularly important time of life when there may be significant issues with respect to social integration following departure from school and pediatric medical services.

Exploration of the determinants of QOL is important for future program planning and service delivery. To date, there have been only a couple of studies that have examined the determinants of QOL for adults,[12,16,17] and, as mentioned previously, these studies have had limitations in terms of the type of QOL instrument used and the generalizability of the findings to young adults with CP. Despite their limitations, previous studies have provided some evidence to suggest that QOL is related to the severity of impairment. For example, a Japanese study of adults with CP showed that CP subtype was related to level of subjective well-being.[16] Inability to perform daily activities was also related to lower subjective feelings of well-being. A study of adults with developmental disabilities living in the United States of America demonstrated that those who engaged in paid employment, schooling, and/or volunteer work were more likely to report higher levels of life satisfaction.[12] Furthermore, in a study of 790 adults with a physical disability, levels of life satisfaction were influenced by employment status and marital status.[17] This empirical evidence is inconsistent with a wealth of ongoing research challenging the theory that disability leads to poor QOL.[7,11,18–20] Whilst is it clear that for children with CP functional status is only weakly related with QOL,[18–22] for adults, issues related to a lack of independence may be associated with lower QOL.

Aims of study

The primary aim of this study was to compare the QOL of a cohort of young Australian adults with CP with a cohort of able-bodied peers, using the same multidimensional instrument. To gain insight into the determinants of QOL, a further aim was to explore the relationship between QOL and impairments, functioning, and social participation.

Methods

This cross-sectional study was conducted at the Royal Children's Hospital in Melbourne, Australia, and ethics approval was granted from the Hospital's Human Research Ethics Committee (EHRC 26117).

Identification of potential CP participants

Young adults ($n = 1007$) born between 1976 and 1985 were identified from the Victorian Cerebral Palsy Register which holds data pertaining to people with CP born in Victoria from 1970 onwards. Those who were known to be deceased ($n = 163$) and those for whom no contact address could be found ($n = 26$) were excluded.

Selection of a general population comparison group

A general population sample of 751 young North American adults, aged 18–25 years, who had completed The Quality of Life Instrument for Young adults (YAQOL),[23] was selected for comparison with the CP sample.

Sample size calculation

Using a hypothesized mean of 85 and a standard deviation of 20, as published by Chen et al,[23] we calculated that a sample of 237 self-reporting CP participants would enable us to find a 10% difference in mean standardized YAQOL scores between the CP and general population groups with 80% power and alpha of 0.05.

Study procedures

Using hospital medical records, an online telephone directory and public access electoral roll, tracing letters were sent to young adults and their families to ascertain whether they would be interested in receiving information about the study and could be contacted at their previously recorded address. Once confirmed, a second more detailed letter was dispatched together with the individually coded survey booklet and the consent form. Individuals who