Self-perceived quality of life of children and adolescents with physical disabilities in Hong Kong

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Abstract

Although illnesses and diseases are thought to adversely affect quality of life (QoL), whether children who have physical disabilities (PD) from a young age adapt to the effect of developmental disabilities has rarely been investigated. This study attempted to assess the subjective wellbeing, and examine the correlation between objective and subjective QoL, of children with PD. Using a self-reported non-disease-specific questionnaire, the QoL of 72 young persons (13.5 ± 2.0 years) with PD was contrasted with those who do not have disabilities (n = 510; age-matched). MANOVA analyses revealed that the PD group had lower objective QoL score (63.0 ± 7.4 vs. 66.8 ± 5.7, p < 0.001) but the two groups were not significantly different in subjective QoL score (70.9 ± 11.4 vs. 69.6 ± 13.6, p = 0.466). No correlation was found between objective and subjective QoL in the PD group (r ranged from 0.06 to 0.19), while weak to medium correlations (r ranged from 0.03 to 0.41) were observed for the controls. The apparent detachment of subjective feeling and objective circumstances in the PD group may reflect adjustment to developmental disabilities.

Key words: Children, Objective quality of life, Physical disability, Subjective quality of life

Abbreviations: ComQoL – Comprehensive Quality of Life Scale; PD – physical disability; %SM – percent of scale maximum

Introduction

The inclusion of quality of life (QoL) as an outcome measure of clinical trials has become the ‘expectation’ rather than ‘exception’ in child health interventions [1–3]. This is based at least partly on two premises. First, QoL is negatively affected as a result of diseases or disorders [4, 5]. Second, the aim of medicine and rehabilitation services is to positively influence the overall wellbeing of the service recipients, and not merely to preserve lives or functions [6, 7]. Although health professionals are often confronted with a variety of QoL measures, there were few tools designed to assess QoL in children and adolescents until the last decade [8]. Eiser and Morse [9] reviewed articles measuring QoL of children and identified 43 instruments, including both health-related and generic measures. There are certain qualities that are consistently associated with QoL measures. First, there is general agreement that QoL is multi-dimensional [8]. It involves a measure of different aspects of a person’s life such as their physical, social and emotional wellbeing, although the exact number of areas or domains and the precise terminology describing these domains varies. For example, Felce [10] defined QoL as ‘an overall general
wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, productive, emotional and civic wellbeing all weighted by a personal set of values’. Second, the domains are usually gauged objectively (often in terms of quantity or frequency) as well as subjectively (in terms of satisfaction) [11, 12]. The measure of subjective satisfaction may also take importance into account. The reason for doing this is that, if a domain (such as material wealth) is not important to an individual, then the level of satisfaction toward this domain is not weighted as high as other domains in this individual’s QoL measure [13].

QoL may be obtained by self-report or proxy responses. In a comprehensive review of child-proxy agreement, Eiser and Morse [14] reported the inter-rater reliability of 14 studies involving over 3000 child-proxy pairs. With the exception of three studies (which included a total of 109 pairs of respondents), the Pearson’s correlations reported ranged from only 0.12 to 0.69, indicating the reliability is, at best, moderate. Child-proxy agreement was found to be particularly low on attributes such as emotional or social wellbeing [14]. Although the literature shows that the QoL of children with illnesses, such as survivors of liver transplantation [15], or with developmental disabilities such as spina bifida [16], is lower than healthy or non-disabled children, these studies usually relied on proxy rating. As such they may be less valid than the child-clients’ own rating of their life quality. Such values are, however, less commonly reported.

There is another reason to measure the self-reported QoL of children. Over the past few years the idea that non-health-related QoL is held under homeostatic control has been developed [17–19]. The Theory of Subjective Wellbeing Homeostasis proposes that, in a manner analogous to the homeostatic maintenance of blood pressure or temperature, subjective QoL is actively controlled and maintained by a set of cognitive buffers that involve self-esteem, perceived control, and optimism. These buffers are normally held in a positive affective state under the influence of personality, and their purpose is to interpret experience in a manner that is self-serving to the individual. Through this means people are able to maintain a positive sense of their wellbeing even while living in challenging circumstances, such as being physically disabled (see [18], for an extended description).

As one consequence of homeostasis, the level of subjective QoL is remarkably stable. While unusually good or bad events will cause mood variations in the short term, over a period of time the homeostatic system will return subjective QoL to a level that is predisposed for each individual [20–22]. At the level of populations the degree of stability is extraordinary. This has been most clearly demonstrated by the application of the Australian Unity Wellbeing Index. Commencing in April 2001, quarterly surveys have been conducted with 2000 Australians, randomly chosen for each survey. Subjective QoL data are standardized to a 0–100 scale. Despite the occurrence of tumultuous international events during the intervening period, the population subjective QoL over the nine surveys conducted to the end of 2003, has varied from 73.2 to 75.9, a range of just 2.7 [23]. Moreover, with the exception of the survey conducted immediately following September 11, the population subjective wellbeing has varied by less than 1 percentage point between adjacent surveys. Such stability is surely comparable to most measures of objective health status averaged across the population over a 3 year period.

With these factors in mind, the present study aimed to adopt a multi-dimensional self-report tool to investigate the effect of physical disability on the QoL of children and adolescents. This study focused on those who were affected by physical disabilities from a young age (e.g., cerebral palsy). In order to ensure that the self-report data were reliable sources of information, this study adopted a QoL tool that was designed for young persons, the Student Version of the Comprehensive Quality of Life Scale (ComQoL) [24]. How much, and in what aspects, these youngsters’ QoL was affected was gauged by contrasting each QoL dimension to those without any physical disabilities. Whether subjective QoL is related to objective QoL was also examined.

**Methods**

**Participants**

For governmental planning purposes in Hong Kong, a person with physical disability (PD) is one