

# SELF-PERCEIVED QUALITY OF LIFE FOR ADOLESCENTS WITH PHYSICAL DISABILITIES — A PRELIMINARY STUDY

Yun-Huei Ju,<sup>1,2</sup> Shwn-Jen Lee,<sup>3</sup> Sing Kai Lo,<sup>4</sup> Hui-Yi Wang,<sup>1,2</sup>  
Hsiao-Chieh Chu,<sup>1</sup> and Jau-Hong Lin<sup>1,2</sup>

<sup>1</sup>Faculty of Physical Therapy, Kaohsiung Medical University, <sup>2</sup>Department of Rehabilitation, Kaohsiung Medical University Hospital, Kaohsiung, <sup>3</sup>Faculty and Institute of Physical Therapy, National Yang-Ming University, Taipei, Taiwan, and <sup>4</sup>Faculty of Health and Behavioral Sciences, Deakin University, Melbourne, Australia.

The purpose of this study was to explore the effect of physical disabilities (PD) on the quality of life (QoL) of adolescents aged from 10 to 18 years. Sixty-three adolescents with PD (aged  $14.9 \pm 2.4$  years) from primary (5<sup>th</sup> grade or above) to high schools in Kaohsiung City volunteered to participate in this research; 282 children without disability (aged  $13.8 \pm 2.3$  years) attending schools in the same geographical region were recruited as controls. The Student Version of the Comprehensive Quality of Life Scale was used in this study. This is a multidimensional self-report, global measure of subjective and objective QoL. Multivariate analysis of variance revealed that the two groups were significantly different in objective QoL ( $F = 11.53, p < 0.001$ ). Material wellbeing was substantially lower in the PD group when compared to the control group. In contrast, domains such as productivity, safety, and emotion were higher in the PD group. Among the subjective scales, the PD group showed higher productivity and better emotion when compared to the control group. No significant correlation was observed between objective and subjective overall QoL scores ( $r = 0.20, p = 0.12$ ) in the PD group. These findings showed that subjects with PD in regular schools demonstrated different patterns in objective and subjective QoL when compared to those without PD. Both subjective and objective domains are important when measuring QoL of adolescents with PD.

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In Taiwan, education and functioning on activities and participation of children with disabilities were enforced with amendments to government laws in 1997 [1–3]. However, a lot of effort has been put into related services such as environmental modification and functional remediation [4], and little attention has been paid to the quality of life (QoL) of these children. Recent studies in medicine and rehabilitation services have emphasized the importance of enhancing the overall wellbeing of the subjects, and not merely to preserve lives or basic functioning

[5,6]. The inclusion of QoL as an outcome measure has gradually become indispensable in child health interventions [7–9].

A complementary review suggested that the concepts of QoL are multidimensional [10], which include physical health, psychological status, social relationship, and environment. On the other hand, QoL should also include objective (e.g., medical and/or economic indicators) and subjective measures (e.g., personal perception and satisfaction), especially for people with physical disabilities (PD) [11,12]. A QoL assessment tool should include different domains [10] that should be measured objectively and subjectively [13]. The Student Version of the Comprehensive Quality of Life Scale (COMQOL-S) is a self-report QoL measure designed for older children and adolescents [14]. It is a global measure of subjective and objective QoL.

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Address correspondence and reprint requests to: Dr Jau-Hong Lin, Faculty of Physical Therapy, Kaohsiung Medical University, 100, Shih-Chuan 1<sup>st</sup> Road, Kaohsiung 807, Taiwan.  
E-mail: [jhlin@kmu.edu.tw](mailto:jhlin@kmu.edu.tw)

An attractive feature about COMQOL is that it includes measures of satisfaction, which is not only a relevant feature, but is also lacking in most other generic measures.

There have been very few studies examining the QoL of adolescents with PD (e.g., polio, cerebral palsy, spinal muscular dystrophy, etc.) in Taiwan. Recognizing their degree of satisfaction and wellbeing of their lives are means of identifying the needs of adolescents with PD, and are of importance for evidence-based policy making by school education boards and government officials. The purpose of this preliminary study was to investigate the effect of PD on the QoL of adolescents in southern Taiwan and to recognize how much and to what degree aspects would be changed by comparing each QoL domain to adolescents without disability. Further, the correlation between subjective and objective QoL was also examined.

## METHODS

### Participants

For the purpose of this study, a person with PD is one “who has disabilities of musculoskeletal, orthopedic, or neurological origin which largely affect locomotor functions, and form an inconvenience or limitation in one or more aspects of daily living activities” [15]. Almost all children with PD in Kaohsiung City are educated in one of 130 integrated or mainstream schools; all such schools were contacted. All youngsters who were able to comprehend the questionnaire according to the schools were invited to participate in the study. A total of 63 adolescents from 22 schools aged between 10 and 18 years (out of a population of 253) agreed to participate in the study. They were in regular classes, except for nine students who were in special classes. Informed consent was obtained from each subject and his/her proxy. Twenty-eight (44.4%) subjects had a diagnosis of cerebral palsy, 10 (15.9%) had

congenital deformities, 5 (8%) had arteriovenous malformations, and 5 (8%) had muscular dystrophy. A quarter of the adolescents had a range of other diagnoses such as accident amputee, brachial plexus injury, poliomyelitis, rheumatoid arthritis, and multiple osteochondroma. This research was conducted with the approval of the Institutional Review Board of Kaohsiung Medical University.

For the normal control, the recruitment was conducted by random selection from 22 schools where subjects with PD in this study were enrolled. Two elementary, three junior and three senior high schools were randomly picked. Researchers randomly selected one class from each school. In total, eight classes were selected. Two hundred and eighty-two young persons without disability and students attending primary, junior, and high schools in the same geographical regions served as our controls. None of the participants in this group had any known physical, neurological, or sensory disabilities that affect their daily function.

### Instrument

This study adopted the COMQOL-S [14]. The English version of the instrument has been well validated [14,16]. Psychometric properties of the Chinese version have also been reported [11]. This instrument measured QoL in subjective and objective perspectives. Both consist of seven domains: material wellbeing, health, productivity, intimacy, safety, place in community, and emotional wellbeing. Each of the seven objective domains contains three items. For example, the health domain comprises the incidence of doctor visits, the grade of disability, and the need for regular medication. All the items in each domain are summarized in Table 1. In total, there are 21 objective items. The possible score range for each item was 1–5; the average score of all the 21 items as well as the mean score for each domain were used for data analysis.

**Table 1.** Items of the objective QoL of the COMQOL-S

Domain	Item 1	Item 2	Item 3
Material wellbeing	Accommodation	Possession	Household income
Health	Doctor visit	Disability	Medication
Productivity	Hours of paid work or school	Spare time	Hours of TV
Intimacy	Chatting with friend	Someone who cares for you	Companion
Safety	Sleep	Home safety	Anxiety
Place in community	Leisure, volunteer work	Responsibility	Others seek your advice
Emotional wellbeing	Control	Active life	Realize wishes

Each subjective domain includes both an "importance" and a "satisfaction" item. For example, the two items for the emotional wellbeing domain are "How important to you is your emotional wellbeing?" (5-point scale), and "How satisfied are you with your emotional wellbeing?" (7-point scale). Hence, there were 14 subjective items. To allow the 5-point importance scale to compare with the 7-point satisfaction scale, the raw scores of these items were transferred to a percentage based on the maximum score (%SM) of the scale. An "important by satisfaction score", which was the product of the two relevant scores, was used for data analysis.

### Procedure

Children with PD finished the questionnaire individually in their schools. Children without disability completed the questionnaire together in their classroom. An investigator was present in case any participant required help in comprehending the question. None of the participants had difficulty in completing the questionnaire on their own. The session was usually for 15–20 minutes.

### Data analysis

The unpaired *t* test was used to compare the overall QoL scores between the two groups. Multivariate analysis of variance (MANOVA) was used to examine the domain scores simultaneously. Pearson correlation was used to

assess the relationship between subjective and objective QoL scores. All analyses were performed using JMP version 5.1.2 (JMP, a Business Unit of SAS, SAS Campus Drive, Cary, NC, USA).

## RESULTS

The PD and control groups were comparable with respect to gender (PD: 57% male *vs.* control: 51%;  $p = 0.41$ ) or age (PD *vs.* normal group in years:  $14.9 \pm 2.4$  *vs.*  $13.8 \pm 2.3$ ,  $p = 0.98$ ). The overall average QoL scores, calculated as %SM were not significantly different between the two groups (objective QoL:  $62.8 \pm 8.4$  *vs.*  $62.8 \pm 8.6$ ,  $p = 0.97$ ; subjective QoL:  $73.5 \pm 10.5$  *vs.*  $70.8 \pm 14.1$ ,  $p = 0.16$ ).

The mean scores for each of the seven domains are shown in Table 2. Regarding the objective score, the material wellbeing was the lowest for the PD group, at about 48.1%SM, followed by place in community, at about 49.6%SM. The scores for health among youngsters with or without PD were the highest, reaching about 83.6% and 84.5%SM. MANOVA analysis indicated that the two groups were significantly different when all the seven objective QoL domains were compared simultaneously. An examination of individual domains revealed that the PD group had significantly poorer objective QoL with respect to material wellbeing; however, they were better in

**Table 2.** Comparison of QoL scores\* between the two groups

	PD ( $n = 63$ )	Normal ( $n = 282$ )	$p^\dagger$
<i>Objective score</i>			
Material wellbeing	$48.1 \pm 13.0$	$60.3 \pm 12.2$	$< 0.001^\ddagger$
Health	$83.6 \pm 12.1$	$84.5 \pm 11.4$	0.557
Productivity	$72.6 \pm 15.2$	$66.6 \pm 17.3$	0.011 <sup>‡</sup>
Intimacy	$58.6 \pm 24.2$	$60.2 \pm 23.7$	0.636
Safety	$70.2 \pm 17.4$	$65.4 \pm 17.0$	0.044 <sup>‡</sup>
Place in community	$49.6 \pm 12.8$	$52.3 \pm 14.4$	0.180
Emotional wellbeing	$56.5 \pm 16.4$	$50.2 \pm 16.0$	0.007 <sup>‡</sup>
<i>Subjective score</i>			
Material wellbeing	$72.9 \pm 13.7$	$70.3 \pm 15.4$	0.213
Health	$73.3 \pm 19.9$	$72.9 \pm 20.5$	0.522
Productivity	$66.6 \pm 12.4$	$61.5 \pm 18.8$	0.039 <sup>§</sup>
Intimacy	$77.7 \pm 15.5$	$74.6 \pm 19.5$	0.238
Safety	$74.8 \pm 15.2$	$72.4 \pm 18.9$	0.353
Place in community	$69.9 \pm 13.3$	$72.0 \pm 18.0$	0.382
Emotional wellbeing	$77.6 \pm 16.6$	$72.1 \pm 20.7$	0.049 <sup>§</sup>

\*Scores reported are %SM  $\pm$  standard deviation; <sup>‡</sup>MANOVA results; <sup>‡</sup>objective QoL:  $F = 11.53$ ,  $p < 0.001$ ; <sup>§</sup>subjective QoL:  $F = 1.54$ ,  $p = 0.15$ . PD = physical disabilities.

**Table 3.** Correlation (Pearson's *r*) between objective and subjective QoL

Domain	Physical disability ( <i>n</i> = 63)	Normal ( <i>n</i> = 282)
Material wellbeing	0.08 ( <i>p</i> = 0.54)	0.18 ( <i>p</i> < 0.01)
Health	0.23 ( <i>p</i> = 0.07)	0.28 ( <i>p</i> < 0.001)
Productivity	0.01 ( <i>p</i> = 0.97)	0.01 ( <i>p</i> = 0.90)
Intimacy	0.22 ( <i>p</i> = 0.08)	0.38 ( <i>p</i> < 0.001)
Safety	0.28 ( <i>p</i> = 0.03)	0.37 ( <i>p</i> < 0.001)
Place in community	0.28 ( <i>p</i> = 0.02)	0.23 ( <i>p</i> < 0.001)
Emotional wellbeing	0.23 ( <i>p</i> = 0.07)	0.39 ( <i>p</i> < 0.001)
Overall (objective <i>vs.</i> subjective)	0.20 ( <i>p</i> = 0.12)	0.45 ( <i>p</i> < 0.001)

productivity, safety, and emotional wellbeing. Regarding the comparison between the two groups' subjective QoL with all the seven domains compared at the same time, MANOVA results showed that there was no significant difference. However, an examination of individual domains revealed that the PD group demonstrated higher productivity and better emotional wellbeing compared to the control group. The differences between the two groups in the other five domains were all within 1–3%SM.

The correlation between objective and subjective QoL is presented in Table 3. For the PD group, no apparent correlation was observed in the material wellbeing, health, productivity, intimacy, and emotional wellbeing domains or the overall average, and the correlation coefficients ranged from 0.01 to 0.23. On the contrary, except in the productivity domain ( $r = 0.01$ ,  $p = 0.90$ ), medium correlation was observed within the normal group in intimacy ( $r = 0.38$ ), safety ( $r = 0.37$ ), emotion ( $r = 0.39$ ), and the overall average ( $r = 0.45$ ).

## DISCUSSION

This study was the first to report comprehensive QoL for adolescents with PD in Taiwan from their self-report. Despite the participants being recruited from Kaohsiung City in southern Taiwan, the control group was also recruited from the same geographical area. The main finding in this study is that adolescents with PD in the mainstream schools of Taiwan expressed an indifferent, subjective QoL compared to their controls even with less objective QoL (e.g., material wellbeing). Subjective and objective QoL were not significantly related in the PD group. These findings indicate the importance of allowing adolescents with PD to express how they feel about QoL; clinicians should measure objective and subjective QoL at the same time for adolescents with PD.

The COMQOL-S is a convincing, short, and comprehensive form for child self-report measures with subjective QoL in the questionnaire. Previous studies [17,18] have shown that the parent's report (or proxy response) and the child's report (or self-perceived) might contribute to the poor agreement on some domains, such as social or emotional status. Self-perception from children about QoL may not be replaced by the parent's report. Moreover, Cummins pointed out the importance of subjective measures in QoL, where subjective QoL is buffered by a set of cognitive characteristics of a person and is unique for him/her to express the experience [19]. Hence, it is necessary to let children themselves respond to the questionnaire and express how they feel. Measuring the child's own QoL, especially in the subjective domain, is of more importance. The COMQOL-S fits with this idea.

People with PD can be impaired across a wide range of QoL domains, including physical, emotional, and social domains. Several studies have shown that negative impacts could be from social, economical, and medical perspectives [20,21]. In our study, adolescents with PD were sampled mainly from mainstream schools (regular or integrated classes). They did not demonstrate significantly different objective and subjective QoL scores compared to the control group. In general, they were as happy and satisfied with what they had, as their peers without any disabilities. Similar results were found in a study in Hong Kong [11]. These findings challenge the impression from the general public that PD negatively affects a youngster's life satisfaction [12].

When measured objectively, students with PD felt safer, had higher productivity, and better emotional wellbeing with fewer material possessions when compared to students without PD. When asked for subjective feelings, students with PD expressed higher productivity and better emotional

wellbeing compared to the control group. Possible explanations could be that students with PD were well-protected by their family, teachers, and peers at home and schools. They might feel safe in this social context. In terms of productivity, students with PD require extra time to accomplish their work or their nonschool hour duties were scheduled for rehabilitation programs, hence they seldom felt flat or bored.

In this study, different patterns of correlation between objective and subjective scales were observed among different groups. Overall, the correlations in the PD group were very low except for safety and place in community. Earlier, similar results were found in a Chinese-speaking population [11]. This may provide evidence that the subjective and objective scales are in fact measuring different perspectives of QoL for persons. It would therefore be critical for professionals to assess objective and subjective QoL separately in adolescents with PD.

Potential limitations of the present study include sampling bias—only subjects from regular schools in local metropolitan districts were recruited. Further studies are required to examine the subjects from other segregated schools as well as different counties and rural regions in Taiwan. Moreover, a comparison between different countries is necessary before the results can be generalized to PD populations. Follow-up study should be planned to collect longitudinal data of the PD group, so that a more comprehensive understanding of QoL changes in adolescents with PD in Taiwan can be achieved. In addition, the impact of PD severity on QoL will be further collected and analyzed in a national study.

In general, students with PD in the regular schools of Kaohsiung City were as happy as their non-PD peers. They might even have higher productivity and better emotional wellbeing compared to their peers. Our results also showed that both subjective and objective scales are important when measuring QoL of adolescents with PD.

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# 肢體障礙青少年自覺生活品質 之初步研究

朱允慧<sup>1,2</sup> 李淑貞<sup>3</sup> 盧成皆<sup>4</sup> 王慧儀<sup>1,2</sup> 朱曉潔<sup>1</sup> 林昭宏<sup>1,2</sup>

<sup>1</sup>高雄醫學大學 物理治療學系

<sup>2</sup>高雄醫學大學附設中和紀念醫院 復健科

<sup>3</sup>陽明醫學大學 物理治療學系暨研究所

<sup>4</sup>澳洲迪肯大學 健康暨行為科學學院

這個初步研究的目的是調查肢體障礙對 10 至 18 歲青少年生活品質的影響。63 位來自高雄市國小 5 年級以上到高中 (職) 學校有肢體障礙的青少年 (平均年齡： $14.9 \pm 2.4$  歲) 願意參加這個研究成為實驗組；同時徵召 282 位來自相同地區沒有肢體障礙的兒童 (平均年齡： $13.8 \pm 2.3$  歲) 做為正常對照組。我們採用學生版全面性生活品質量表，以多面向、自我闡述的一般性問卷方法來測量肢體障礙兒童和青少年對於生活品質的客觀和主觀感受。多變項分析結果顯示這兩組在客觀生活品質方面是有明顯的差異性 ( $F = 11.53$ ,  $p < 0.001$ )，享有物質方面在肢體障礙組是明顯低於正常控制組；相反地，肢體障礙組在成就感、安全感、快樂感等方面得分高於正常組。而主觀生活品質感受方面，成就感和快樂感方面得分也是高於正常組。然而，對於肢體障礙組而言，主觀生活感受及客觀測量生活品質的得分之間並沒有統計學上的相關性 ( $r = 0.20$ ,  $p = 0.12$ )。這些結果似乎顯示在一般學校的肢體障礙和正常青少年主觀和客觀生活品質之間存在不同層面的差異性；對於肢體障礙學童，同時測量主觀感受和客觀生活品質的重要性。

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通訊作者：林昭宏教授

高雄醫學大學物理治療學系

高雄市 807 十全一路 100 號