

AGREEMENT BETWEEN CHILD SELF-REPORT AND PARENT PROXY-REPORT TO EVALUATE QUALITY OF LIFE IN CHILDREN WITH CANCER

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SUMMARY

Assessment of children's Quality of life (QOL) is a special challenge for clinicians and researchers because different cognitive abilities of children at various ages and illness levels are so varied. In addition, statistical strategies reported to evaluate proxy agreement have been inconclusive. The specific aims of this study were to examine agreement between child self-reports and parent proxy-reports to evaluate QOL in a sample of pediatric cancer patients. Previously tested QOL instruments (Quality of Life for Children with Cancer, QOLCC) were completed by 141 patients (82 children and 59 adolescents) and 141 of their parents. Three different statistical approaches were employed to evaluate convergence of self-report and proxy-report: product-moment correlation coefficient, intraclass correlation (ICC), and comparison of group means. In addition, scatter bias was used to examine the degree of differences across the range of measurement. Our findings indicate that neither Pearson product correlation, ICC or group difference provided enough information to detect the individual differences of measures of QOL. We found that scatter bias should be supplemented to quantify the degree of individual-level differences. The results suggest that when children who are younger are not able to evaluate QOL assessment due to their developmental limitation or severity of illness, parents can provide valid information about their QOL. However, parent-proxy of QOL for adolescents provides significantly different information than self-report and proxy data of QOL for adolescents should be used with caution. Copyright © 2004 John Wiley & Sons, Ltd.

Assessment of health-related quality of life (QOL) has become a more important concern for pediatric cancer patients because advances in cancer treatment have improved survival rates (Levi *et al.*, 2001). QOL has been recognized as a subjective judgment (Allison *et al.*, 1997) because its assessment relies on self-reported data. Assessment of children's QOL is a special challenge for clinicians and researchers as different cognitive abilities of children at various ages and illness levels vary so much. Thus, attention to these issues is essential when developing clinical and research tools to assess or measure their QOL. Others have suggested using multisource and multimethod data collection techniques to collect data in studies of

children and adolescents (Holmbeck *et al.*, 2002). Proxy-report may be the only resource of data when children are too young to understand the content of self-report measures or too sick to answer a questionnaire. However, inconsistent proxy-report between patients (children within different age groups) and parents have been reported frequently in the literature (Parsons *et al.*, 1999; Theunissen *et al.*, 1998; Varni *et al.*, 1998). It is important to determine whether the proxy-report is valid and therefore could be used to assess child's QOL when their self-report data is not possible to obtain.

Statistical strategies used to examine proxy agreement in QOL have not reached consistency. In a review of research reports that compare children's self- and proxy-reports of QOL (Eiser and Morse, 2001), the most common strategies used to examine the children's self-report and parent-proxy of QOL include Pearson

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product-moment correlation coefficients, k statistics, comparison of group means, intraclass correlation coefficient (ICC) (Tamim *et al.*, 2002). These methods each have limitations. For example, it is argued that in using Pearson r that high association does not provide evidence of good absolute agreement between methods (Brown *et al.*, 1992). In an assessment of agreement about health related QOL between Dutch children and their parent proxies, large mean differences were found for physical complaints, while the correlation coefficient was larger than 0.5 (Theunissen *et al.*, 1998). It has also been argued that in group mean comparisons significant discrepancy may exist at the individual level but not be detectable at the aggregate level (Marshall *et al.*, 1994). Intraclass correlation coefficients can be used to take into account both systematic mean differences and the relative ordering of different respondents (Shrout and Fleiss, 1979), but it is not sensitive to systematic differences in the mean level of responding (e.g., instances in which every individual differs by a constant) (Marshall *et al.*, 1994). Following the suggestion of Bland and Altman (1986), Marshall *et al.* (1994) have strongly suggested strategies to establish the extent of agreement between patient self- and proxy-reports, including examination of correlation coefficients; group means differences, intraclass correlation as well as scatter bias to examine the individual differences between items.

The validity of proxy-report has been observed more in objective assessment than subjective perspectives in the literature. Agreement of proxy-reports, using the criteria of Pearson r larger than 0.5 (Eiser and Morse, 2001), was generally found in objective assessments, such as physical activities (Varni *et al.*, 1998; Theunissen *et al.*, 1998); functioning and symptoms (Eiser *et al.*, 1995; Varni *et al.*, 1998). The literature assessing the agreement between children' and parent proxy-report of QOL is sparse. Thus, we examined the validity of parent proxies based on the suggestions of Bland and Altman (1986) as well as Marshall *et al.* (1994). More specifically, this study examines agreement between child reports and parental proxy-reports to evaluate QOL in a sample of pediatric cancer patients using different approaches to evaluate convergence of self-report and proxy-report using product-moment correlation coefficient, intraclass correlation, and comparison between group means and individual differences).

METHOD

Subjects

Data were collected from eligible children with cancer and their parents (hereafter, participants) in treatment at outpatient clinics and in a hospital ward of the Chang Gung Children's Hospital, a large medical center in Taiwan. In total, 168 patients and their parents were approached; 13 patients and 22 parents declined to participate due to time constraints. A total of 155 patients and 146 parents participated in the study.

Procedure

The hospital's established procedures for protecting confidentiality were strictly followed. Eligible parents were approached by one of three trained data collectors who are registered nurses. They received verbal and written explanation of the study and procedures and asked about their willingness to participate with their ill children in our study. After parental consent and child assent were obtained, participants were sequentially scheduled and interviewed face to face at the hospital ward. Each patient and one of his/her parents were provided with a questionnaire packet, including a pre-stamped envelope. The packets were collected either immediately after completion at the facility or by mail if the participants could not complete the questionnaire while in the hospital. A reminder call was made if packets were not received within two weeks after distribution. In total, 13 patients and their parents took the questionnaire home and mailed their package back to the research office. All participant identification on the surveys was removed immediately upon returning the packet and all materials were stored in a locked office.

Measures

Quality of Life for Children with Cancer (QOLCC) (Yeh and Hung, 2003; Yeh *et al.*, 2004a, b). QOLCC was developed in our previous studies in Chinese language. QOLCC consisted of a total of 34 items and is designed to measure the impact of disease and treatment on the child's

appraisal and satisfaction of functioning in the five domains: (1) *physical function*, defined as functional status in the activities of daily living; (2) *psychological function* defined as the degree of emotional distress; (3) *social function*, defined as interpersonal functioning in peer/school relationships; (4) *treatment/disease-related symptoms*, defined as anxiety and worry about the illness and treatments; and (5) *cognitive function*, defined as cognitive performance in problem solving. Two subscales of Understanding illness and Communication pattern were also included in QOLCC. For each item, patients were presented with four graded responses: 0, Never; 1, Sometimes; 2, often; or 3, always being a problem. The sum of items in each scale provides a score for each domain. The total score of QOLCC was the sum of each scale. Higher scores reflect more symptoms or health-related problems. Hence, it indicates a more negative impact on the patient and thus a lower QOL. To accommodate the differences in cognitive ability of children and adolescents, two versions of the same instrument were created for children aged 7–12 years (QOLCC-7-12); and adolescents aged 13–18 years (QOLCC-ADO). The younger children's version is simplified linguistically. The Parent proxy-report form (QOLCC-PAR) contained all the elements of the patient version, but was presented in third-person tense. Our previous studies have demonstrated good reliability and construct validity for these instruments. (Yeh and Hung, 2003; Yeh *et al.*, 2004a, b). The reliability of each subscale ranged from 0.69 to 0.79 (Yeh *et al.*, 2004b). The construct validity was examined by confirmatory factor analysis and all of the subscales reached certain degree of excellent overall fits model (including the ratio of chi square to degrees of freedom, the goodness-of-fit index, and the root-mean-square error of approximation) (Yeh *et al.*, 2004b). The feasibility of the QOLCC was confirmed by a high rate of data completeness, acceptable floor and ceiling effects, and clinical validity for on- and off-treatment groups (Yeh and Hung, 2003).

DATA ANALYSIS

In this study, for the purpose of analysis the data were divided into two main groups: the Child Group and the Adolescent Group. The two groups

were determined by the age of the patients, i.e., children (≤ 12 years) and adolescents (> 12 years), in order to decrease methodological problems caused by the differences in the amount and quality of parental caregiving for younger children and adolescents (Perrin *et al.*, 1991) and potential disagreement between parents and adolescents' self-rating of QOL (Yeh, 2001). The answers of missing items of QOLCC were replaced by the means of the subscale for each subject, before further statistical analysis.

In order to compare the differences between parent proxy-report and patient self-report, the mean scores and standard deviations were summarized separately. To evaluate the differences between patients' and proxies' report, the means of the absolute differences, the means of the differences (mean bias) (patient group–parent group) and the standard deviation of difference were computed (Bland and Altman, 1986). A mean bias less than zero indicates that the parents tend to overestimate the negative impact of the patients and a mean bias greater than zero indicates that parents tend to underestimate it. The effect size d was used to examine the magnitude of this bias, defined by the ratio of the mean difference by the SD of the mean score (Novella *et al.*, 2001). The value of the d was judged by the guideline provided by Cohen (1992): $d = 0.2$ was categorized as a small effect size, $d = 0.5$ a medium effect size, and $d = 0.8$ a large effect size. Agreement between the children and parents was further quantified using Pearson correlation coefficients and the intraclass correlations (ICC) (Marshall *et al.*, 1994; Shrout and Fleiss, 1979). Scatter bias was used to examine between-method difference at the individual level (Marshall *et al.*, 1994). The magnitude of bias was calculated by predicting the difference between patient and proxy-reports from the average scores obtained by the two methods (Hays *et al.*, 1995). The ICC was estimated by two-way random effects model as a ratio of between-client to total variance, where total variance includes variation between clients and within clients (Shrout and Fleiss, 1979). The values of Pearson product correlation coefficient effective size were categorized as small, medium, and large when correlation coefficient were smaller than 0.3, between 0.3 and 0.5, or equal or larger than 0.5, respectively (Cohen, 1992). The judgment of the ICC follows the same criteria as the Pearson product correlation coefficient.

RESULTS

The participants in this study included 155 children, diagnosed with cancer and 146 parents of these children ($N = 301$). Since the study purpose was to examine the agreement of children's self- and parent proxy-report, thus the data analysis was based on the 141 matched sets (including 141 parents and 141 patients, $N = 282$). The parent group included 13 primary caregivers who were not parents. For clarity, the children are referred to as patient participants and the parents are referred to as parent participants.

Characteristics of participants

Demographic characteristics of participants were provided in Table 1. There were 82 children and 59 adolescents in the study. All patients, including 91 male and 50 female, were between 7 and 18 years of age at the time their cancer diagnoses. Forty-nine percent of patients were newly diagnosed and under treatment, but without relapses; 11% of patients were under treatment for relapses, and 40% of patients had completed treatment. Mean age of the patients was 11.78

years (range 7.2–17.9, S.D. = 3.71). Their cancer diagnoses included leukemia (58%), lymphoma (15%), and other solid tumors (27%).

The mean age of mothers was 38.95 (range 26–52, S.D. = 5.04), and their mean education was 10.25 years (range 6–16, S.D. = 2.70). The mean age of fathers was 42.40 (range 27–68, S.D. = 5.77), and their mean education was 11.18 years (range 6–18, S.D. = 2.49). Except for partial payments by patients' families, medical expenditures for cancer treatment were covered by the national health-care insurance of Taiwan.

Reliability and mean differences of QOLCC

The means, standard deviations of parent-child discrepancy scores and reliability of the seven subscales of QOLCC and the overall QOLCC are presented in Table 2 for Children (<12 years) and Adolescent (≥ 12 years). For the Child Group, Cronbach's alpha coefficients for the multi-item subscales ranged from 0.63 (Social subscale) to 0.89 (Physical subscale) for each subscale. For the Adolescent Group, the Cronbach's alpha coefficients for the multi-item subscales ranged from 0.67 (Psychological subscale) to 0.86 (Communication subscale) for each subscale.

In order to compare the rank order of each subscale, the mean item score of each subscale seen in Table 2 was represented as the ratio of the sum of subscale score over the number of items in the subscale. The distribution of mean item scores for all subscales for Child and Adolescent Groups are presented in Figures 1 and 2. Children and their parents had the highest mean in the subscale of Understanding while Adolescents and their parents had the highest mean in the subscale of Disease/Symptom.

Indices for differences between self and proxy-reports of QOLCC are provided in Table 3. For the Child Group, the mean of the absolute values of differences between patient and proxy ranged from 0.35 (Physical subscale) to 0.74 (Understanding subscale) for each subscale and 0.49 for total scales. This result indicates that children and parents had the largest discrepancy on the Understanding subscale. For the Adolescent Group, the mean absolute differences are largest for the subscales of Psychological and Understanding, which indicate less agreement of these subscales than for the other subscales.

Table 1. Demographic characteristics of patients ($N = 141$)

Variables	N (141)	%
Age		
≤ 12 years	82	58
> 12 years	59	42
Gender		
Male	91	65
Female	50	35
Diagnosis		
Leukemia	82	58
Lymphoma	21	15
Other solid tumors	38	27
Illness stages		
Newly diagnosed	22	16
Under treatment but in remission	46	33
Under treatment for relapses	15	11
Completed treatment	58	40
Socioeconomic status		
1 (Highest)	1	1
2 (Moderately high)	10	7
3 (Medium)	40	30
4 (Moderately low)	60	44
5 (Lowest)	24	18

Table 2. Mean, standard deviation, and reliability of self-reports and proxy-reports of quality of QOL ($N = 141$)

Subscale		Number of items	Mean ^a	Standard deviation	Reliability
<i>Children</i>					
Physical	Self-reports	5	0.62	0.64	0.78
	Parent proxy		0.48	0.70	0.89
Psychological	Self-reports	6	0.76	0.57	0.71
	Parent proxy		0.63	0.55	0.84
Social	Self-reports	4	0.48	0.49	0.63
	Parent proxy		0.37	0.40	0.64
Disease/symptom	Self-reports	4	0.76	0.58	0.72
	Parent proxy		0.85	0.51	0.66
Cognitive	Self-reports	6	0.77	0.59	0.78
	Parent proxy		0.69	0.59	0.87
Understanding	Self-reports	4	1.49	0.79	0.71
	Parent proxy		1.45	1.01	0.88
Communication	Self-reports	5	0.80	0.71	0.77
	Parent proxy		0.76	0.61	0.80
Qoltot	Self-reports	34	0.84	0.43	0.88
	Parent proxy		0.75	0.41	0.91
<i>Adolescents</i>					
Physical	Self-reports	5	0.62	0.61	0.81
	Parent proxy		0.28	0.37	0.74
Psychological	Self-reports	6	0.91	0.74	0.85
	Parent proxy		0.48	0.42	0.67
Social	Self-reports	4	0.60	0.54	0.70
	Parent proxy		0.35	0.42	0.70
Disease/symptom	Self-reports	4	0.94	0.64	0.80
	Parent proxy		0.80	0.54	0.78
Cognitive	Self-reports	6	0.91	0.55	0.80
	Parent proxy		0.61	0.48	0.75
Understanding	Self-reports	4	0.69	0.69	0.77
	Parent proxy		0.63	0.68	0.77
Communication	Self-reports	5	0.82	0.80	0.86
	Parent proxy		0.65	0.57	0.84
Qoltot	Self-reports	34	0.84	0.43	0.89
	Parent proxy		0.57	0.32	0.87

Qoltot = Quality of Life total score.

^aMean = sum of total subscale score divided by the items number in the subscale.

Group mean differences are also shown in Table 3. Proxy respondents had a tendency to overestimate QOLCC compared to the patients' reports. For the Child Group, except for the subscales of Disease/Symptom, Understanding and Communication, all other subscales and the total scale show statistically significant differences between the Child and Parent reports. For the Adolescent Group, only Disease/Symptom, Understanding and Communication did not reach statistically significant differences between the Adolescent and Parent reports. The magnitude of

mean bias, defined by the effect size d , was small for all of the significant difference for the Child Group and medium for the Adolescent Group.

Agreement indices for self versus proxy-reports of QOLCC are provided in Table 4. For the Child Group, Product-moment correlations between proxy and patient reports for corresponding QOL subscales ranged from 0.21 (communication, medium correlation) to 0.65 (physical, high correlation) ($p < 0.05$), indicating a medium to high degree of association. Intraclass correlations were almost equal to or smaller than product-moment

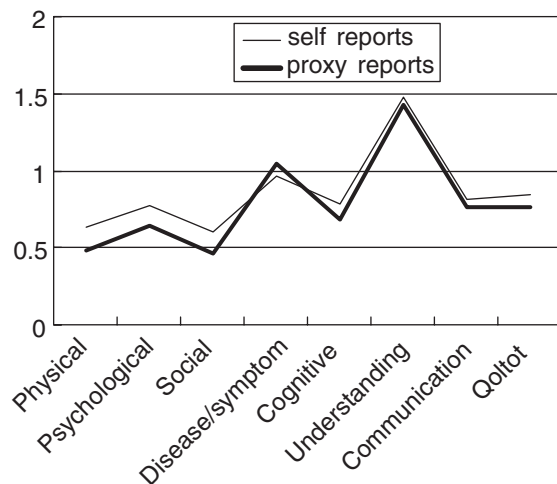


Figure 1. The mean differences between Child report and Parent Proxy-report.

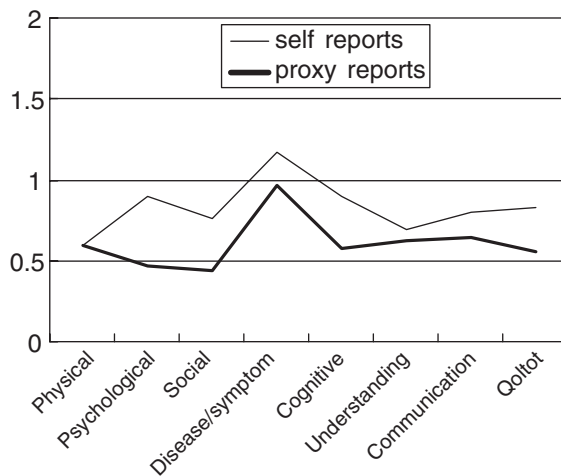


Figure 2. The mean difference between Adolescent and Parent Proxy-report.

correlations (Table 4). Except for the subscale of communication, all other subscales had moderate to high correlation among the Children and the Parent Proxy Group. However, for the Adolescent Group, only Social, Disease/Symptom, Cognitive and Communication subscales and total scale show moderate correlations.

Scatter bias differences did not reveal statistically significant differences on either each subscale or total scale for the Child Group except for the

subscale of Understanding. For the Adolescent Group, scatter bias was evident for the subscales of Physical, Psychological, Social and Communication as well as the total score. Greater differences were seen between self and proxy-reports for adolescents with worse functioning in physical, psychological, social, and communication domains and lower overall QOL. Although the overall mean difference of communication of group mean comparison was not statistically significant, scatter bias was evident. This result indicated that the subscale of Communication had differences at the individual level, but not at the aggregate level.

DISCUSSION

This study used different statistical strategies to examine the agreement of patient self-report and parent proxy-report of QOL assessment for children with cancer. Before the interpretation of the findings, two limitations of this study should be noted. First, the proxy-report data included 13 caregivers. We included the 13 caregivers in the parent proxy report data since these caregivers had cared the patients most time and had the ability to assess the patients' QOL. In addition, 13 questionnaires were completed at home, different from those completed at face-to-face interviews, which may influence the results. The statistical strategies included Pearson correlation, Intraclass correlations, paired *t* test associated with differences between group means and scatter biased *t*-ratio on individual scores. Our findings suggest that parent proxy-reports are more valid for children who are younger than 12 years but less for parents and adolescents.

When comparing mean scores of patients and their proxies, statistically significant differences were noted for four subscales (Physical, Psychological, Social, and Cognitive) and total scale for the Child Group. However, the magnitude of this bias was relatively small for all four subscales and total scale. Mean bias was statistically evident for four subscales (Physical, Psychological, Social, and Cognitive) and total scale for the Adolescent Group. The effect size for this bias was medium. There was a consistent bias for parental proxies to underestimate the negative impact of disease and treatment for the patients. The analysis of the mean bias between patients' and proxies' reports

Table 3. Mean differences between self-reports and proxy-reports ($N = 141$)

Measures	Mean absolute differences ^a	Mean bias ^b	S.D. of difference	Effect size d^c
<i>Children</i>				
Physical	0.35	0.16**	0.52	0.31
Psychological	0.44	0.14*	0.58	0.24
Social	0.43	0.15*	0.60	0.25
Disease/symptom	0.52	-0.07	0.68	-0.10
Cognitive	0.40	0.12*	0.51	0.24
Understanding	0.74	0.04	0.96	0.04
Communication	0.60	0.07	0.84	0.08
Overall QOL	0.49	0.09*	0.38	0.24
<i>Adolescents</i>				
Physical	0.39	0.32***	0.59	0.54
Psychological	0.55	0.36***	0.69	0.52
Social	0.48	0.32***	0.59	0.54
Disease/symptom	0.51	0.10	0.77	0.13
Cognitive	0.43	0.24***	0.54	0.44
Understanding	0.55	0.08	0.76	0.11
Communication	0.53	0.19	0.75	0.25
Overall QOL	0.49	0.24***	0.37	0.65

^a Mean of absolute difference between parent-child pairs.

^b Child group mean-parent group mean.

^c Effect size d = mean difference/S.D. of mean difference.

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

indicated that there were more coherent reports between patients and proxies for the Child Group than for the Adolescent Group.

According to Marshall *et al.* (1994), the examination of Pearson correlation and ICC provide a piece of useful evidence to evaluate the degree of agreement. In this study, the subscales of QOLCC showed moderate to high correlations for Child Group and parent proxy, except for the Communication subscale. Pearson correlation has been most used approach to examine the proxy validity and has been referred as the level of agreement (Eiser and Morse, 2001). Bland and Altman (1986) have criticized that published research studies have often used Pearson correlation coefficients as an indicator of agreement between the results of two measurements and conclude 'it is no such thing' (p. 307). Pearson correlation coefficient only measures the strength of a relation between two variables, rather than agreement (Bland and Altman, 1986).

Due to the insufficiency of Pearson correlation coefficient, group differences should be used to further supplement information provided by

correlation coefficients (Marshall *et al.*, 1994). In the current study, Disease/Symptom and Understanding with moderate level of correlations show the absence of between group differences for the Children group, indicating that children and parent have good agreements in these two subscales. However, the use of group difference has been criticized suggesting that individual differences may not be detectable at the aggregate level (Marshall *et al.*, 1994). Therefore, the degree of the discrepancies could be assessed via scatter bias to examine the variation across the range of possible scores (Bland and Altman, 1986). The scatter bias of regressing between-method differences (child-parent) against the mean of scores obtained by the two methods in Child Group showed no statistically significant differences among all the subscales and total scale for the Child Group and Parent Proxy, except for the subscale of Understanding. The absence of scatter bias indicated differences between child reports and proxy-reports were generally unrelated to the child's level of QOL. Thus, we have confidence to state that parent proxy-report of QOL could serve

Table 4. Agreement between self-reports and proxy-reports ($N = 141$)

Measures	R	ICC	Paired t test	Scatter bias t -ratio ^a
<i>Children</i>				
Physical	0.68***	0.68***	2.68**	-0.50
Psychological	0.48***	0.48***	2.24*	0.40
Social	0.42***	0.41***	2.25*	1.94
Disease/symptom	0.51**	0.51***	-0.90	1.55
Cognitive	0.61***	0.60***	2.12*	0.83
Understanding	0.45***	0.44***	0.38	-2.33*
Communication	0.20*	0.22*	0.72	1.34
Overall QOL	0.58***	0.58***	2.20*	0.25
<i>Adolescents</i>				
Physical	0.37**	0.33**	4.13***	4.17***
Psychological	0.37**	0.33**	4.01***	4.50***
Social	0.52***	0.50***	4.13***	2.12*
Disease/symptom	0.47***	0.46***	1.06	1.01
Cognitive	0.46***	0.46***	3.50***	1.07
Understanding	0.37**	0.39**	0.81	0.42
Communication	0.49***	0.45***	1.92	3.77***
Overall QOL	0.56***	0.52***	4.97***	2.77*

R = Pearson product-moment correlation.

ICC = Intraclass correlation.

^a Regressing (child score - parent score) against (child score + parent score/2).

* $p < 0.05$.

** $p < 0.01$.

*** $p < 0.001$.

as a substitute report for children who are younger than 12 years when they are not able to provide self-report assessment of QOL.

In contrast, for the Adolescent Group, scatter bias was evident in the subscales of Physical, Psychological, Social and Communication as well as the total score. Greater differences were seen between self- and proxy-reports for adolescents with more negative impact of disease and treatment than for adolescents with less impact. Thus, proxy data provide significantly different information than self-reports for assessing the individual adolescent patient. This finding is consistent with a study that assessed QOL for children with asthma and found that parents can provide little information about quality of life for children who are older than 11 years (Guyatt *et al.*, 1997). Consistent with the literature (Guyatt, 1999), parents tend to report better QOL for adolescents with cancer. For health workers, the assessment of QOL for adolescent (who are older than 12 years in this study) should be based on adolescent's self-reported data. Parent proxy can only be used as supplemental information.

Literature supports that proxies tend to have validation on objective assessment (such as hyperactivity, acting out), rather than subjective assessment (depression and anxiety) (Achenbach *et al.*, 1987; Varni *et al.*, 1998, 1999). Inconsistent with published literature that proxy-reports are shown more validity in objective assessments (physical functioning in QOLCC) than subjective assessment (psychological functioning in QOLCC), our findings did not reach the same conclusion. Our findings indicate that parent proxy agreement is only validated at the subscales of Disease/Symptom, Cognitive and Understanding for the Adolescent Group. We have proposed several explanations for the high concordance among these subscales. First, we further examine the duration of illness in Adolescent Group and found that more than 70% of adolescent had their illness over 6 months at the time of data collection. Adolescent may go back to school after their illness treatment protocol or side effects have stabilized. In Taiwan, when a patient hospitalized, a family member is needed to accompany with patient. A family member (usually parents in this

study) can observe the disease/symptom when an adolescent is hospitalized, thus we expected there to be valid concordance between adolescent and parent proxy-reports. On the other hand, the cognitive functioning assessed in this study focuses on schoolwork and memory. School performance still has been prioritized by Taiwanese parents after the cancer has been diagnosed (Yeh, 2001). In addition, adolescents in our study appeared to be more mature than their healthy peers due to their illness, thus their developmental ability help them to understand what is going on with them (Yeh, 2001) although there is not much open discussion of illness between parents and children.

Taken together, this study employed different statistical strategies to examine the agreement of QOL for children with cancer from patient self- and parent proxy-report. The findings showed that either Pearson product correlation, ICC or group difference did not provide enough information to detect the individual differences of measures of QOL. We suggest that the use of scatter bias to examine individual differences should be further examined to quantify the degree to which discrepancies vary across the range of possible scores. The results have the implication that when children who are younger than 12 years are not able to evaluate QOL assessment due to their developmental limitation or too sick to answer it, parents can provide valid information about their QOL. However, parent-proxy of QOL for adolescents provides significantly different information than self-report at the group and the individual levels. Thus, proxy assessment of QOL for adolescents may not provide a useful substitute and should be used with caution.

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