Brief communication

Validation of the English version of the KINDL® generic children's health-related quality of life instrument for an Asian population – results from a pilot test

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Abstract

Objectives: To evaluate the psychometric properties of the KINDL questionnaire in an Asian population. *Methods:* Consecutive patients with diabetes mellitus (DM) and healthy subjects were recruited to complete the English KINDL questionnaire. The inclusion criteria for patients were age 8–16 years, English-speaking, diagnosed with DM and absence of co-morbid conditions. *Results:* Thirty children with DM (mean age: 10.7 ± 1.35 years; 11M) and 39 healthy subjects (mean age: 10.6 ± 1.23 years, 17M) completed the child version whereas 31 adolescents with DM (mean age: 14.5 ± 1.48 years; 15M) and 32 healthy subjects (mean age: 14.3 ± 0.87 years, 16M) completed the adolescent version. Overall, children with DM reported better HRQoL than healthy children. Although this appeared counter-intuitive, several explanations are possible: (1) the development of resilience to the disease over time, (2) our subjects are well-managed, (3) response shift, (4) the provision of high quality medical care, (5) compared to normal children, diabetic subjects and their family pay greater attention to health issues. The reliability coefficients were (overall, scales): KINDL-Kid DM (0.79, 0.44–0.65), KINDL-Kid Healthy (0.71, 0.60–0.80), KINDL-Kiddo DM (0.77, 0.37–0.74) and KINDL-Kiddo Healthy (0.84, 0.21–0.79). *Conclusions*: The KINDL questionnaire appeared promising for use in Asian children. However, further validation in a sample more representative of the general population is required.

Key words: Asia, Child, Cross-cultural comparison, Psychometrics, Quality of life

Introduction

Traditional measures of health such as infant mortality rate, expected life expectancy and biochemical markers, are limited in the information they provide on health outcomes of pediatrics with chronic illnesses [1]. Health-related quality of life (HRQoL), which describes the impact of illnesses on the physical, mental and social aspects of patients' lives, provides a more comprehensive measure of health outcomes in children [2–5]. Hence, there is an increasing interest to measure HRQoL in children.

The WHO defined HRQoL as 'the individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns [6].' It is thus clear that cultural factors play an important role in HRQoL assessment. To-date, almost all existing children HRQoL measures were developed in the West, based on a Western notion of health and illness. However, these instruments are also frequently used outside of the socio-cultural context in which they were originally developed, thus giving rise to two important issues.

First, do the two cultures (the original and the target cultures) share the same concepts of HRQoL? [7] This is particularly important because if the two cultures have divergent concepts of

HRQoL, then a reliable instrument will simply be measuring the wrong thing efficiently. The second issue is whether the HRQoL instrument can retain its measurement properties (reliability, validity and responsiveness) across different cultures? [7, 8] An instrument that does not measure what it is supposed to measure (i.e., validity), does not produce consistent results (i.e., reliability) and is unable to measure changes over time will not be a useful tool at all.

Worldwide, there is a growing interest in the measurement of HRQoL. However, the application of HRQoL as a research tool in Asia has been hampered due in large part to the lack of suitable HRQoL instruments. This problem is particularly acute in the pediatric population. Fortunately, in recent years, increasing number of instruments to assess HRQoL outcomes in children has been developed [9, 10]. Yet, only very few instruments are culturally adapted and validated for use in Asia [11–14]. One major difficulty in culturally adapting these new instruments is that Asia is culturally diverse and her people speak a variety of languages. Nevertheless, English is widely spoken in this region. For example, Singapore, Malaysia, Hong Kong and the Philippines have a long history of English usage [15–18]. Thus, an English version of generic children's HRQoL instrument will find wide application in this region and is urgently needed. To the best of our knowledge, a culturally adapted and validated English version of generic HRQoL instrument for children has not been made available yet. Singapore, an island state located in Southeast Asia with a population of 4 million, is a very Westernized multiethnic Asian society with English as the language of teaching in all schools and thus serves as an excellent test case for the purpose of this study.

The aim of our study is to make available a suitable generic child HRQoL instrument for use among Asian children. There are several approaches to developing children's HRQoL instruments (e.g., extrapolating from adults' instrument, expert opinion and focus group discussion with children and their parents [19] and it is well-accepted that the approach which directly involved children during the development phase is most relevant and useful. Yet, few children's HRQoL instruments have taken this most useful approach. The KINDL-questionnaire is one of

them. We have thus selected this instrument for the purpose of our study. We aimed to evaluate the reliability and validity of the KINDL-questionnaire (a generic children's HRQoL instrument) in an Asian pediatric sample.

Methodology

The instrument

The KINDL-questionnaire originally developed in Germany is available in several languages including English. The KINDL-questionnaire may be used with permission from the developers (www.kindl.org). The KINDL-questionnaire comes in three age versions: KINDL-Kiddo (13–16 years), KINDL-Kid (8–12 years) and KINDL-Kiddy (age 4–7 years) with both parents and self-reports. In this study, we have used the self-report versions for the KINDL-Kid and KINDL-Kiddo. The KINDL-questionnaire is developed from a conceptual model that included four main components of HRQoL, namely psychological well-being, social relationships, physical functions and everyday-life activities [20]. It comprises twenty-four items yielding six dimensions (physical health (PH), general health (GH), family functioning (FAM), self-esteem (PER), social functioning (FREN) and school functioning (SCH)) and a total score (Appendix). Reverse scoring is applied to some items and the total score is transformed to a scale of 0-100 such that higher score represents better HRQoL.

Cultural adaptation

Cultural appropriateness of the KINDL-questionnaire for the Singapore context was assessed. A pediatric endocrinologist (LWWR), who comes into daily contact with children due to his job nature, reviewed the cultural relevance of the contents – and assessed the appropriateness of the level of language of the KINDL-questionnaire for use among Singaporean children. The KINDL-questionnaire was subsequently pre-tested in eight subjects representing as wide a spectrum as possible (composition: 6 diabetic and 2 healthy subjects, 5 girls and 3 boys, age: 8–15 years). The subjects were asked to identify items, words or phrases that they found difficult, irrelevant or ambiguous. They

were then asked to suggest alternatives for these problematic items, words or phrases.

Subjects and study design (main study)

After informed consent, consecutive patients with diabetes (both type 1 and 2) seen at the Kandang Kerbau Women and Children's Hospital (the major pediatric hospital in Singapore) between December 2000 and February 2001 were invited to participate. The inclusion criteria were age 8–16 years, English-speaking, diagnosed with diabetes, absence of co-morbid conditions and ability to complete the questionnaire without assistance. A fieldworker checked through the questionnaire to ensure completeness of data. Healthy subjects were randomly recruited outside three community libraries located in different parts of Singapore. Only subjects who gave a negative response to the question 'Are you suffering from any long-term sickness such as asthma or diabetes?' were recruited. The KINDL-questionnaires were also self-administered by the healthy subjects.

Method of analysis

Ceiling and floor effects were computed for all KINDL scales. Reliability (internal consistency) was assessed by Cronbach's alpha. Construct validity was examined by investigating the instrument's ability to discriminate between diabetic and healthy subjects using a known-group approach [21]. Diabetic subjects were expected to report lower scores on the KINDL-questionnaire. Data were expressed as means with SD unless indicated otherwise. For group comparisons, the Student's *t*-test was applied. All statistical analyses were performed with Statistical Package for the Social Sciences (SPSS) 11.0 for Windows [22].

Results

Cultural adaptation

Minor changes to the original questionnaire were proposed and accepted by the developer (Table 1). The subjects did not know the meaning of 'worn-out' and this was omitted in the Singapore version of the questionnaire. The item Were you staying in

Table 1. List of changes to the original KINDL items following cross-cultural adaptation (revisions were underlined)

Original items	Revised
Put a cross in the box	Put a tick in the box
Which type of school?	Deleted
I am in the ___ grade	KINDL-Kid:
	I am in Primary ___
	and
	KINDL-Kiddo:
	I am in Secondary ___
I was tired and worn-out	I was tired
Were you staying in hospital just now or do you have some long-term illness?	(a) Were you staying in hospital just now?
	(b) Do you have some long-term illness?
NIL	Are you taking or going to take medicine for a long time?

hospital just now or do you have some long-term illness? was modified because the subjects found it confusing.

Main study

A total of 69 subjects completed the KINDL-Kid (diabetic: n = 30, mean age: 10.7 ± 1.35 years, 11 males; healthy: n = 39, mean age: 10.6 ± 1.23 years, 17 males) whereas 62 subjects completed the KINDL-Kiddo (diabetic: n = 31, mean age: 14.5 ± 1.48 years, 15 males; healthy: n = 32, mean age: 14.3 ± 0.87 years, 16 males, Tables 2 and 3). All questionnaires were completed without any missing responses. The distribution of responses, ceiling and floor effects and reliability of the individual scales in KINDL-Kid and – Kiddo were reported in Tables 4 and 5 respectively. Compared to healthy subjects, ceiling effects are more prominent in diabetics. Significant ceiling effects among diabetic subjects are found in the PH, GH, FAM and FREN in both the KINDL-Kid and -Kiddo. Floor effects were negligible in both diabetic and healthy subjects. The KINDL-Kiddo demonstrated better reliability (i.e., higher Cronbach's alpha) than the KINDL-Kid. At the same instance, the KINDL-Kiddo demonstrated discriminant validity while the KINDL-Kid did not. Diabetic subjects completing the KINDL-Kiddo reported significantly higher overall scores than healthy subjects (diabetic vs. healthy:

Table 2. Distribution of respondents and median HRQoL score in the KINDL-Kid by demographic factors

| | KINDL-Kid | | | | | |
| | N (%) | | Score (SD) (%) | | Range | |
	Patients	Control	Patients	Control	Patients	Control
All	30	39	70.3 (12.57)	62.5 (10.76)	38.5–100	44.8–93.8
Gender						
Male	11 (36.7)	17 (43.6)	70.1 (23.16)	63.2 (11.6)	38.5–100	44.8–93.8
Female	19 (63.3)	22 (56.4)	81.8 (16.64)	64.3 (9.82)	56.3–86.5	53.1-81.3
Age						
8	2 (6.7)	2 (5.1)	68.7 (17.68)	56.3 (2.95)	56.3–81.3	54.2–58.3
9	5 (16.7)	6 (15.4)	70.0 (14.92)	60.6 (8.32)	50.0–87.5	54.2–74.0
10	6 (20.0)	9 (23.1)	67.7 (26.93)	70.3 (13.55)	37.5–100.0	53.1–93.8
11	5 (16.7)	10 (25.6)	76.3 (22.71)	60.6 (10.92)	37.5–93.8	44.8–74.0
12	12 (40.0)	12 (30.8)	79.7 (22.79)	64.1 (8.81)	31.3–100	52.1–81.3
Mean (SD)	10.7 (1.35)	10.6 (1.23)	–	–	–	–
Ethnicity						
Chinese	22 (73.3)	27 (69.2)	76.1 (20.01)	61.7 (11.20)	37.5–100.0	44.8–93.8
Malay	3 (10.0)	7 (17.9)	70.8 (31.46)	66.2 (6.67)	37.5–100.0	57.3–75.0
Indian	4 (13.3)	5 (12.8)	62.5 (25.52)	71.0 (10.56)	31.3–93.8	53.1–81.3
Others	1 (3.3)	0	93.8 (–)	0 (–)	–	–

Maximum Possible Score = 100%.

72.9 ± 10.82 vs. 61.3 ± 11.28, $p = 0.001$). Subjects completing the KINDL-Kid showed similar trend but the difference was not statistically significant. At the scale level, diabetic subjects completing the KINDL-Kiddo scored consistently higher than healthy subjects across all scales. However, in the KINDL-Kid, the trend was absent.

Table 3. Distribution of respondents and median HRQoL score in the KINDL-Kiddo by demographic factors

| | KINDL-Kiddo | | | | | |
| | N (%) | | Score (SD) (%) | | Range | |
	Patients	Control	Patients	Control	Patients	Control
All	31	32	72.9 (10.82)	61.3 (11.28)***	43.8–90.6	33.3–81.3
Gender						
Male	15 (50.0)	16 (50.0)	68.7 (12.61)	58.9 (12.62)	43.8–87.5	51.0–79.2
Female	15 (50.0)	16 (50.0)	74.6 (9.41)	63.8 (9.53)	56.3–90.6	33.3–81.3
Age						
13	12 (34.3)	4 (12.5)	66.8 (10.21)	66.7 (10.88)	47.9–81.3	52.1–75.0
14	7 (20.0)	17 (53.1)	75.3 (15.39)	63.9 (11.50)	43.8–90.6	41.7–81.3
15	6 (17.1)	7 (21.9)	72.4 (9.52)	54.6 (11.4)	56.3–82.3	33.3–66.7
16	6 (17.1)	4 (12.5)	75.0 (8.00)	56.8 (4.71)	63.5–84.4	51.0–62.5
Mean (SD)	14.5 (1.48)	14.3 (0.9)	–	–	–	–
Ethnicity						
Chinese	21 (60.0)	19 (59.4)	71.9 (8.98)	58.8 (10.89)	57.3–90.6	33.3–79.2
Malay	3 (8.6)	0 (0.0)	66.7 (13.87)	–	47.9–75.0	–
Indian	9 (25.7)	6 (18.8)	77.1 (13.37)	64.4 (10.65)	43.8–87.5	47.9–81.3
Others	2 (5.7)	0 (0.0)	68.8 (17.68)	–	56.3–81.3	–

Maximum Possible Score = 100%.
*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

Table 4. Score distribution, ceiling and floor effects and reliability of the KINDL-Kid scales

Scale	Score (SD) (%)		Ceiling (%)		Floor (%)		Reliability (Alpha)		
	Patient	Control	Patient	Control	Patient	Control	Patient	Control	All
Physical (PH)	81.3 (21.49)	75.0 (16.15)	13.3	10.3	0.0	0.0	0.65	0.42	0.55
General (GEN)	84.4 (18.62)	75.0 (16.60)	16.7	5.1	0.0	0.0	0.62	0.46	0.54
Self-esteem (PER)	46.9 (23.92)	37.5 (25.22)	3.3	5.1	6.7	7.7	0.63	0.80	0.72
Family (FAM)	68.8 (17.42)	75.0 (16.89)	10.0	2.6	0.0	0.0	0.54	0.25	0.36
Social (FREN)	59.4 (22.17)	68.8 (15.43)	10.0	2.6	0.0	0.0	−0.19[a]	0.07	0.11
School (SCH)	75.0 (13.71)	56.3 (18.25)***	13.3	0.0	0.0	0.0	0.63	0.29	0.46
All	70.3 (12.57)	62.5 (10.77)	3.3	0.0	0.0	0.0	0.79	0.71	0.75

[a]Score improved to 0.44 after reverse scoring was applied.

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

Discussion

We found the KINDL-Kiddo questionnaire to be a valid and reliable instrument for measuring HRQoL in Asian children. The internal consistency of the KINDL-Kiddo scales was generally high and the KINDL-Kiddo was capable of differentiating between diabetic and healthy subjects. Overall, the KINDL-Kiddo demonstrated better measurement properties (i.e., lower ceiling effects, higher reliability, better discriminant validity) than the KINDL-Kid. The high ceiling effects and relative low reliability in KINDL-Kid were causes for concern.

In the present study, we made two unusual findings. First, one of the KINDL-Kid scales returned a negative Cronbach's alpha (theoretical value of Cronbach's alpha lies within 0–1). To verify the negative value in the KINDL-Kid, we checked the data for error and made certain that reverse scoring was applied, where necessary. In this case, item 4 of FREN scale ('I felt different from other children') should be and was reversely scored (Appendix 1). A correlation analysis was then performed and negative correlations between this item and the other items in that scale were found. Therefore, we suspected that this item, which measured a negative construct in the European study [20], measured a positive construct instead in our sample. We then 'reversed' the scoring, treating this item as a positive construct and recalculated the reliability coefficients. Among subjects completing the KINDL-Kid, Cronbach's alpha increased from −0.19 to 0.44 (diabetic) and from 0.07 to 0.60 (healthy). However, among subjects completing the KINDL-Kiddo, reversed scoring reduced Cronbach's alpha from 0.45 to 0.44 (diabetic) and from 0.55 to 0.31 (healthy). Therefore, the suspicion that this item might have measured a positive construct appeared to be valid at least in younger Singaporean subjects. The results suggest that a different scoring system may need to be devised for younger Asian children. However, more work is needed to study how the FREN scale functions among Asian children before any changes in scoring system can be recommended.

Table 5. Score distribution, ceiling and floor effects and reliability of the KINDL-Kiddo scales

Scale	Score (SD)%		Ceiling (%)		Floor (%)		Reliability (Alpha)		
	Patient	Control	Patient	Control	Patient	Control	Patient	Control	All
Physical (PH)	77.0 (18.43)	67.6 (16.22)*	12.9	0.0	0.0	0.0	0.65	0.64	0.65
General (GEN)	79.0 (19.54)	70.1 (17.00)	22.6	6.3	0.0	0.0	0.69	0.69	0.68
Self-esteem (PER)	50.8 (25.25)	41.2 (20.69)	0.0	0.0	3.2	6.3	0.74	0.79	0.75
Family (FAM)	83.1 (15.83)	74.0 (13.39)*	35.5	6.3	0.0	0.0	0.67	0.49	0.62
Social (FREN)	82.3 (14.44)	68.4 (14.54)***	19.4	0.0	0.0	0.0	0.45	0.55	0.57
School (SCH)	56.0 (17.42)	46.7 (14.46) *	0.0	0.0	0.0	0.0	0.37	0.21	0.31
All	71.4 (11.24)	61.3 (11.28)**	0.0	0.0	0.0	0.0	0.77	0.84	0.84

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

Second, diabetic subjects reported better HRQoL than healthy subjects, reaching statistical significance on the KINDL-Kiddo. Although some studies have failed to detect a difference in HRQoL among sick and healthy pediatrics [20, 23, 24], however, to the best of our knowledge, none has reported a finding similar to ours. This peculiar finding may be explained by a combination of the following reasons. First, it is possible that diabetic subjects refrained from reporting adverse HRQoL outcomes. Studies have reported that young diabetics would show resilience in terms of their self-esteem, behavioral problems and overall adjustment to the disease [25]. Second, it is likely that the diabetic conditions of our subjects are generally well-controlled. Third, it is also possible that our subjects have undergone a 'response shift' [26], where they have adjusted their own expectation of life, following a bad experience with poor health or even near death experience (for those subjects who were diagnosed only after an episode of diabetic ketoacidosis). Fourth, provision of high quality medical care may minimize the impact of the disease on patients' HRQoL, thus reducing the disparity between healthy and sick children. [20] In addition, it is likely that the diabetic subjects and their parents and/or health care providers pay closer attention to certain aspects of health more than 'healthy' children and their families, e.g., diet, exercise and emotional well-being. Last, adjustments made on the part of the parents may also be responsible for the better HRQoL observed in diabetic children. For example, in Singapore, there is a very strong emphasis on academic excellence. The accompanying mental stress may compromise the HRQoL of healthy children. Furthermore, parents may have lower expectation of their children's academic performance if their children were suffering from a long-term disease. Hence, given that the HRQoL of healthy children could have been compromised in the pursuit of academic merit, and that the impact of diabetes on patients' HRQoL would be minimised if the condition were well managed, it would not be surprising to find that children with diabetes reported better HRQoL. Nevertheless, given that the observation may be peculiar to diabetic subjects in Singapore, the construct validity of the KINDL-questionnaire needs to be confirmed using a different disease population.

We recognized several limitations of this study. First, we have reported the ceiling and floor effects as an indicator of the usefulness of the KINDL-questionnaire for detecting changes. However, a more useful treatment of the issue is the detection of the situation in which a patient improves (or deteriorates) but the score derived from the measure does not (i.e., an assessment of the responsiveness of the instrument). Future studies should address this issue by adopting a longitudinal design and to incorporate other measures of clinical assessment. Second, the relatively low internal consistency observed in KINDL-Kid was worrying. However, for group level comparisons, minimum reliability levels of 0.50 and 0.70 have been suggested [27, 28] The lower reliability reported for healthy controls may be related to the heterogeneity of the sample or a true lack of reliability. For instance, among the 'healthy' controls, some may have experienced recent episodes of acute medical conditions (such as upper respiratory tract infections, gastroenteritis, headaches and injuries) that impair HRQoL. On the other hand, for the diabetic subjects, any episodes of acute medical conditions are likely to receive prompt attention from parents and healthcare providers and thus have limited impact on HRQoL. However, among diabetic subjects who completed the KINDL-Kid, the minimum value of 0.50 for Cronbach's alpha was achieved on all six scales. Hence, we were inclined to believe that heterogeneity of the sample accounts for the poorer reliability observed among healthy controls. Third, we have chosen to perform a convenience sampling of patients and healthy subjects which may limit the generalizability of the findings of this study to the general population. However, as this is a pilot study, generalizability to the general population is not our primary research objective.

Conclusion

The KINDL-Kiddo questionnaire is a promising generic HRQoL instrument for use among Asian adolescents. However, the internal consistency of KINDL-Kid requires further study. In addition, the construct validity of both KINDL-Kid and Kiddo needs to be confirmed in a different disease population.

Acknowledgement

Appendix (Items in the KINDL-Kid and KINDL-Kiddo)

KINDL-Kid	KINDL-Kiddo
Physical Scale	
PH1 … felt ill	PH1 … felt ill
PH2 … headache or tummy-ache	PH2 … in pain
PH3 … tired and sleepy	PH3 … tired and sleepy
PH4 … strong and full of energy	PH4 … strong and full of energy
General scale	
GEN1 … had fun and laughed a lot	GEN1 … had fun and laughed a lot
GEN2 … bored	GEN2 … bored
GEN3 … felt alone	GEN3 … felt alone
GEN4 … scared	GEN4 … was scared or unsure of myself
Personal scale	
PER1 … proud of myself	PER1 … proud of myself
PER2 … felt on top of the world	PER2 … felt on top of the world
PER3 … felt pleased with myself	PER3 … felt pleased with myself
PER4 … had lots of good ideas	PER4 … had lots of good ideas
Family scale	
FAM1 … got on well with my parents	FAM1 … got on well with my parents
FAM2 … felt fine at home	FAM2 … felt fine at home
FAM3 … quarrelled at home	FAM3 … quarrelled at home
FAM4 … stopped from doing certain things	FAM4 … felt restricted by my parents
Friends scale	
FREN1 … played with friends	FREN1 … did things together with my friends
FREN2 … other kids liked me	FREN2 … was a 'success' with my friends
FREN3 … got along well with my friends	FREN3 … got along well with my friends
FREN4 … felt different from other children	FREN4 … felt different from other people
School scale	
SCH1 … doing my school work was easy	SCH1 … doing my school work was easy
SCH2 … enjoyed my lessons	SCH2 … found school interesting
SCH3 … looked forward to the weeks ahead	SCH3 … worried about my future
SCH4 … was afraid of bad marks or grades	SCH4 … was worried about getting bad marks or grades

Statistical worksheet
Worksheet 1. Item reduction analysis.

Scale removed	KINDL-Kid % score (SD)		KINDL-Kiddo % score (SD)	
	Patients	Control	Patients	Control
None	70.3 (12.57)	62.5 (10.76)	77.0 (18.43)	67.6 (16.22)
General health	68.1 (12.90)	61.3 (11.46)	69.8 (11.02)	46.1 (8.87)
Personal	73.8 (12.64)	67.5 (10.18)	75.5 (10.41)	65.4 (11.30)
Family	69.4 (13.00)	61.3 (11.16)	69.0 (12.05)	58.8 (11.57)
Friends	71.3 (13.14)	60.0 (11.73)	69.2 (12.01)	59.9 (12.08)
School	66.3 (13.57)	63.8 (10.74)	74.4 (12.31)	64.3 (11.76)

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