# Meaning of health-related quality of life among children and adolescents in an Asian country: A focus group approach

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#### Abstract

Aims: We aimed to evaluate the extent to which HRQoL instruments developed based on the Western notion of health is applicable to Asian children and adolescents by assessing their conceptualization of QoL. A secondary objective is to evaluate the necessity of developing age- or gender-specific HRQoL instruments. Methods: We explored the meaning of general and health-related QoL through focus group discussions in Singapore, a multi-ethnic Asian society. Two investigators independently analysed the data. They extracted major and sub-themes related to both general and health-related QoL. The agreement between the analyses was compared and disagreement was resolved through discussion. Results: Thirty-two subjects (children: 50.0%, female: 50.0%) participated. There were few disagreements. Meanings of general and health-related QoL could be grouped under three broad themes: (1) physical, (2) psychological and (3) social health, consistent with the current definition of HRQoL. We found that Singaporean and Western children/adolescents share a remarkably similar notion of general and health-related QoL. Compared to adolescents, children were more likely to report positive emotions, be less mindful of others' opinions and had less varied social activities. Conclusion: The results suggest that currently available instruments are potentially useful for Singaporean children/adolescents. We also found that age-specific HRQoL instruments are necessary.

Key words: Cross-cultural comparison, Focus group, Pediatrics, Quality-of-life

Abbreviations: HRQoL - Health-Related Quality-of-Life

#### Introduction

Health-related quality of life (HRQoL) assessment is increasingly common among children and adolescents and covers diverse clinical areas including haematology [1], asthma [2] and rheumatic diseases [3]. In measuring HRQoL among children/adolescents, attention should be given to the selection of suitable HRQoL instruments. This is particularly so if the instrument is to be used outside the culture in which it was developed [4].

Generally, there are three main approaches to the development of HRQoL instruments for children and adolescents. In the first approach, instruments for children and adolescents were adapted from existing instruments for adults. Given that children and adults have different life experiences and priorities and therefore do not necessarily share the same meaning of health and illness, this approach is likely to be of limited value [5], unless the developers make conscientious effort to ensure that the contents are valid (i.e. meaningful) and the instruments are reliable (i.e.

consistent) for assessment of child HRQoL. The third approach, which we shall discuss later, will be particularly useful for assessing content validity. In the second approach, opinions of 'experts' were sought to select items considered important to children and adolescents for constructing the HRQoL instruments. This approach shares the same limitations as the first in that the choice of items by adult 'experts' is likely to be colored by their own values, experiences and expectations [5]. The last and most desirable approach involves children themselves, sometimes together with parents and healthcare professionals. Unfortunately, few developers have taken this approach. In this approach, children and adolescents were asked directly to report or discuss issues that are important to them. For example, the Children's Dermatology Life Quality Index was developed by asking 169 children and adolescents aged 3–16 years to write down, with help from parents when required, how their skin disease affected their lives. However, this study did not allow for group interactions, which are useful for understanding complex behaviors and motivations behind ideas [6]. Three studies that employed the focus group methodology, which allows for group interaction, in design of HRQoL instruments for children and adolescents were identified. Cramer et al. [7] developed the Quality of Life in Epilepsy Inventory for Adolescents (QOLIE - A) through focus group discussion with adolescents [7]. Content validity of OOLIE-A was reported based on the observation that comments derived from focus group discussions did not reveal new content areas that were not already covered in the questionnaire. However, as the contents used in the focus group are largely derived from adult QoL instruments, framing effects may be of concern here [5]. The Canadian Haemophilia Outcomes - Kids Life Assessment Tool was also developed based on items elicited from focus group discussion involving children and their parents [8]. However, the number of subjects in that study was relatively small. The European KIDSCREEN Group is the largest identified study which involved both sick and healthy children in focus group discussions during the development of HRQoL questionnaires [9].

The focus group methodology is not new and has been extensively employed in the fields of communications studies, marketing, education and political science amongst others [6]. Morgan defined the focus group as a research technique that collects data through group interaction on a topic determined by the researcher [6]. An important feature of the focus group approach is the 'group effect' where interactions between participants give rise to more information than can be obtained from multiple individual interviews. For a detailed discussion of the inherent strength and limitations of the focus group methodology, readers are referred to the work by Morgan [6]. However, the application of focus group as a research tool in the field of HRQoL is still in its infancy. Eiser and Morse [5] commented that current focus group studies that involved children tended to be poorly described with little detail about how the content of discussion is transformed into questionnaire items. Clearly, better designed studies are needed to demonstrate the value of focus group discussion as a useful tool in constructing HRQoL instruments.

To-date, almost all HRQoL instruments for children and adolescents were developed in Western countries [10]. The extent to which these instruments are useful in Asian children and adolescents remains to be determined. It is a fact that Asians and Westerners view health differently. For example, in East Asia, health is viewed as the maintenance of a balance between Yin and Yang in the body and that illness is a result of an imbalance [11, 12]. However, in the west, illness is perceived as a consequence of an external force, such as a virus or bacteria, or a slow degeneration of the functional ability of the body. As a result, the two cultures may conceptualize HRQoL very differently. Hence, the first objective of this study is to evaluate the extent to which instruments developed based on a Western notion of health are useful among children and adolescents in an Asian country. In addition, some instrument developers designed different age versions of the HRQoL instruments to cater to developmental differences [13–16]. Boys and girls also undergo significant developmental differences. However, we are not aware of any gender-specific HRQoL instruments for children/adolescents, although such instruments are available in the adults. Hence, the second objective of this study is to evaluate the need to develop separate versions

of the questionnaire for children/adolescents and boys/girls.

## **Objectives**

- To determine the extent to which HRQoL questionnaires developed based on the Western notion of health is applicable to Asian children and adolescents in a community-based sample in Singapore.
- 2. To evaluate the need to develop separate versions of HRQoL instruments for children/adolescents and boys/girls.

#### Methodology

## Subjects

In this community-based study, subjects were recruited from a student-care centre (which provides after-school care for children with working parents), one boy school, one girl school and a mosque in Singapore. Approval for participation in the focus group study was sought from the principals, teachers or person-in-charge regarding recruiting participants for focus group discussions. Participants were selected by the principal, teacher or person-in-charge. The principal, teacher or person-in-charge was encouraged to select the participants by using a random number table. Inclusion criteria were ability to understand English and ability to provide logical answers to questions as assessed by the principal, teacher or person-in-charge. Informed consent was obtained from the parents of all participating subjects.

Socio-demograhic variables including age, gender, number of brothers and sisters, ethnicity, grade, type of housing, family income and self-reported health status were collected. The participants were then divided according to their age into children (8–12-years-old) and adolescents (13–16-years-old). A total of eight focus groups was planned with each group comprised of four subjects of the same gender and same-age bracket. The advantage of limiting the group composition to same-gender would be the elimination of any confounding effect of gender on communication [17]. The number of groups, the gender mix and

the sample size for the study, were based on the focus group protocol used by the European KIDSCREEN group [9].

#### Procedure

Each discussion was moderated by the same moderator, who was an undergraduate in the final year of Pharmacy course using standardised questionnaire to ensure consistency. The structure of the focus group discussion and the questionnaires used were adopted and modified (with written permission from the developers) from the guidelines used by the European KIDSCREEN group [9, 18]. All sessions were conducted in classroom setting and the participants were seated around a square table. At the beginning of each session, the moderator informed the participants about the objectives and approximate duration of the interview. The moderator also informed the participants that he or she may refuse to answer any questions or stop the interview at any time, that interviews would be anonymous and confidential and that he or she had complete freedom of expression. The session begun with a general question, "In your opinion, what is important for you in your everyday life to make you feel well?" and respondents were allowed to talk until no new views were expressed. Throughout the discussion, interference from moderator was kept to the minimal and limited to preventing the participants from digression. The sessions were video- and audio-taped to facilitate content analysis. The reason for recording the interview was communicated to the participants. An abridged transcription of the audio tape recording was carried out by the moderator. The exact expressions used by the participants were conserved in the transcripts. The transcript was checked for accuracy against the video recording by an independent postgraduate student (involved in health outcomes research) who was not involved in the focus group discussion. The video tape was also viewed to observe respondents' behaviour during the course of the discussion

# Structure of focus group discussion

Each focus group session was divided into four sections. A list of questions covering major

domains of life (Table 1) was provided to help the moderator facilitate the discussion. In Section 1, themes that were spontaneously brought up by the subjects were collected. The contents would thus reflect the meaning of general QoL to children and adolescents. The participants were encouraged to be as specific as possible by means of questions such as "That is to say?", "Can you be more specific?", "Can you explain that in more detail?" or "How is this manifested in your daily life?". Participants were free to express their views.

During Section 2 which was more directive, the participants were asked to express physical, psychological and social repercussions related to health status. Hence, the meaning of HRQoL to children and adolescents were addressed in this section. Sample questions were listed in Table 1. Again, participants were prompted to explain and/or elaborate on their answers. A 10-minute break

followed the conclusion of Section 2. During the break, refreshment was served.

In the next section after the break, a paper-and-pencil round, we gathered children and adolescents' opinions on themes extracted from existing Quality of Life scales for children/adolescents – the KINDL Generic Children's Questionnaire (KINDL) and the Generic Children's Quality of Life Measure (GCQ). A total of 12 themes (mobility, energy, self-esteem, cognitive functioning, friends, family, living condition, autonomy, behaviour, emotions, pain/discomfort and self-care) were extracted from both questionnaires. Asking participants to comment on all 12 themes would impose tremendous respondent burden. Hence, each participant commented on only a subset of four themes.

A small token of appreciation for their time and contribution was presented to each participant at the conclusion of the focus group session.

Table 1. Sample questions used in focus group

Meaning of general quality of life

- 1. In your opinion, what is important for you in your everyday life to make you feel well?
- 2. How have you been feeling?
- 3. What do you like best about your life?
- 4. What bothers you most in your life?
- 5. What makes you feel happy?
- 6. What makes you feel unhappy/sad?
- 7. What were the things you did this week/month?
- 8. Were there any interesting events that happened this week/month?
- 9. What do you usually do during the holidays?
- 10. What about your family?
- 11. What about your friends?
- 12. How do you feel about school?
- 13. Do you have any fears?
- 14. Do you think about the future?

Meaning of health-related quality of life

- 1. When a child/adolescent is ill, what change in his/her everyday life?
- 2. Have you been already ill?
- 3. Is it important to be healthy?
- 4. When do you feel healthy?
- 5. Do you feel healthy recently?
- 6. What keeps you healthy?
- 7. Do you try to keep yourself healthy?
- 8. What do you prefer to do during your leisure time?
- 9. How will a child/adolescent like you feel when your family member/friend is ill?
- 10. Who are the most important persons around you?
- 11. Can a child/adolescent of your age be worried?
- 12. Can a child/adolescent of your age feel stressed?
- 13. How do you feel about visiting see the Doctor/Dentist?
- 14. How do you feel about taking medicines?

#### Data analyses

The data were analysed based on the grounded theory approach [19], independently by the moderator and a second investigator (the postgraduate student involved in health outcomes research) who did not attend the focus group discussion. First, major themes related to both general and health-related QoL were extracted from the discussions in Sections 1 and 2. Second, sub-themes were identified and classified under the relevant major themes. Lastly, participants' opinions on existing themes of QoL (Section 3) were examined to evaluate the relative importance assigned to these themes. When the analyses were completed, the moderator and the postgraduate student met up to compare the agreement between the two analyses. Areas of discrepancies were highlighted and resolved through discussion. In the event that the moderator and the postgraduate student were not able to reach a consensus, a neutral third-party would be asked to join in the discussion. All discrepancies must be resolved.

#### Results

# Subjects

Thirty-two children and adolescents (50% female, 72% Chinese, 19% Malay, 3% Indian and 6% other ethnicities) participated in the focus group discussions. The multi-ethnic makeup of the focus group represents the multi-ethnic nature of the Singaporean population.

## Analysis

Each focus group session lasted an average of 90 min. Some groups of participants (usually the adolescents) preferred to finish all four sections without a break. However, the moderator still gave a 5-min break after Section 2 so that participants would maintain their concentration throughout the study. The two sets of data analyses were in high agreement with each other. Data saturation was observed. Results from the discussion on meaning of general and health-related QoL could generally be grouped under three broad themes: (1) physical, (2) psychological and (3)

social health. Within each theme, the discussion could be further classified under sub-themes. From the discussion, we were also able to identify items or events that may be used in the construction of quality of life questionnaires (Table 2).

## General Quality of Life

## Physical health

A central theme in the discussion was physical health. Two important sub-themes that emerged were: (1) adoption of health-promoting life-style, and (2) having sufficient sleep. During the discussion, the participants brought up the importance of proper meals, regular exercises, the avoidance of certain types of food (such as fast food and food of too high salt and oil content), and the need of abstinence from alcohol and smoking. Although the participants advocated adoption of healthpromoting behaviour (i.e. healthy diet and regular exercise), a few admitted that they do not practise it. For example, a participant commented that it was very troublesome to stay healthy. Participants also said that having sufficient sleep is very important to their physical health. For example, a participant said that he would feel 'groggy', and another said that she has been feeling tired because of insufficient sleep.

# Social health

The next major theme that emerged was social health. The impact of family and friends were frequently mentioned throughout the discussion. Friends and family were generally cited as source of support and fun although some participants also expressed some negative views such as nagging mother and disturbing younger siblings. Play was also mentioned as an important component of the participants' social health. One participant said the things he liked best about his life are "riding bicycle and playing computer games because it is fun". One participant said that he was happy when he played soccer. Another said that she was happy when she played with her brother. A third participant said that he was glad school holiday was approaching as he would have more time to play. Another interesting aspect arising from the discussion was that the school emerged clearly as an important social interacting environment for the participants. Many of the activities that children

and adolescents carried out were within school compound.

## Psychological health

Three sub-themes related to psychological functioning were identified from the discussion. These were: (1) positive emotions, (2) negative emotions, and (3) self-esteem. The positive emotions expressed by the participants included 'happy', 'glad' and 'satisfied'. Participants were happy when they scored good grades in school. Holidays, good food and recreational activities were also important for them to feel happy and satisfied. Some participants also reported that they felt happy and satisfied when their material needs (e.g. new toys) were met. The negative emotions

that participants expressed included 'stressed', 'bored' and 'depressed'. For example, participants were stressed up with examinations. Some said life was boring as it was preoccupied with lessons and schoolwork. Many participants also felt depressed when they did not perform well in their examinations. Several participants described that conflicts with family members and restrictions of freedom made them unhappy. One of the groups lamented about social insecurity brought about by terrorism and the recent severe acute respiratory syndrome (SARS) epidemic. Discussion related to self-esteem included fear of rejection by friends and fear of failing examinations. Some participants were also concerned about their appearance and peoples' opinions of them. Again,

Table 2. Summary of major themes and items that arose from focus group discussions

Domain categories	Item meanings	
	Child	Adolescent
Physical health		
Physical activity	Skipping	Skipping
	Jogging	Jogging
	Cycling	Cycling
	Swimming	Swimming
Diet	Consumption of fruits and vegetables	Consumption of fruits and vegetables
Sleep	Feel tired	Feel tired
Dexterity	Play computer games	Play computer games
Psychological		
Positive and negative emotions	Нарру	Нарру
	Worried	Worried (too many options in life)
	Sad	Sad
	Fear (of injections and death)	Bored
Self-esteem		Appearance
		People's opinions
Social		
Family	Do things together	Do things together
	Nagging from parents	Nagging from parents
	Scolding from parents	Arguments with parents and siblings
	Bullied by siblings	Faced restrictions in what they can do
	Shopping	Participate in Recreational activities
	Travel	
	Parents bought toys	
	Health of family members	
Friends	Do things together	Do things together
	Disturbed by friends	Watch movies
	Chatting	Baking
	Play	Chatting
		Peer pressure
		Support
School	Academic performance	Academic performance
	Scolding from teachers	Scolding from teachers
	Work load	Work load

school (or more accurately academic performance) featured rather prominently in psychological health.

## Health-related Quality of Life

The meaning of HRQoL to our study participants may similarly be divided into three major themes: physical, psychological and social health (Table 2).

#### Physical health

When the participants were asked to discuss about the changes that occurred when a child/adolescent fell ill, two important sub-themes emerged: (1) restriction in activities and (2) effects of medications.

The main impact of illness on physical health was restriction of activities. Typically, the response from children and adolescents could be summarised as follows:

"Because have to rest all day, can't play. Cannot do anything, sleep everyday." (Child)

"Can't go around doing stuff." (Adolescent)

Medications have mixed effects on participants' physical health. In general, the participants considered taking medication as an unpleasant task. Some participants complained that the medications were too sweet (with specific reference to cough syrup) while others complained that the medications were too bitter (with specific reference to traditional Chinese medicine). Interestingly, some participants said they like their medicines because they tasted sweet. Participants also complained that they felt very tired, drowsy, lethargic and have problems concentrating after taking certain medications.

# Social health

Illness was also perceived to negatively affect social interactions. For example, some participants commented that friends might avoid them because of fear of catching the disease. Others commented that they could not go out to play with friends and they could not communicate well when they fell ill. There was also the fear of missing lessons due to absence from school.

#### Psychological health

The greatest impact of illness appeared to be on psychological health. Many participants said that they felt 'miserable', 'down', 'frustrated', 'sad' and some even cried when they fell sick. One participant also revealed the fear of death. Generally, the repercussions of falling ill were perceived as increase in homework load due to absence from school and falling behind others in academic performance.

#### Children vs. adolescents

Some differences in contents and intensity of discussion between children and adolescents were observed. First, children and adolescents assigned different level of importance to the three broad domains of health. For instance, when asked "What is important for you in your everyday life to make you feel well?", children only talked about physical health. Adolescents, on the other hand, discussed physical, psychological and social health. In another instance, when participants were asked "When do you feel healthy?", children again referred only to physical aspect of health (e.g. after exercise, with healthy diet, when not sick, etc). Adolescents, however, referred to both physical and psychological aspects of health (e.g. when not feeling stressed, when not sick, when happy, after exercise, etc).

Second, we observed that children reported positive emotions more frequently than adolescents. For example, in expressing their general QoL, children described more positive emotions, using terms such as 'happy', 'excited' or 'glad'. On the other hand, adolescents expressed more negative emotions, using terms such as 'depressed', 'stressed' and 'tired'. Related to this observation, adolescents discussed the importance of having sufficient sleep a lot more often than children.

Third, adolescents were very mindful of others' opinions. They worried about their physical appearances and body images. On the contrary, none of the children discussed anything related to appearance.

Fourth, we also observed that the social activities of children were limited to family and school while adolescents had a wider range of social activities. For example, adolescent girls talked

about going for movies or baking cookies together with friends and adolescent boys talked about going for sports training.

Fifth, children expressed fear for the metaphysical unknown, including darkness, ghosts and being alone. Adolescents, on the other hand, conceptualized fears in terms of failure and rejection rather than the metaphysical unknowns. One group of adolescent boys even claimed that they did not have any fears. In relation, children said they were scared to see doctors or dentists while adolescents said that they had grown out of the fear. A common expression used was "I used to be scared of doctors but now I'm used to it."

Lastly, when children were asked to think about their future, they considered both the immediate (e.g. school results) and the distant future (i.e. their ambitions). Some even made considerations on financially supporting their family. The adolescents, in contrast, considered only the distant future (e.g. ambitions, marriage and family planning as well as financial planning). Interestingly, some of the adolescent boys said that "there is no need to think about the future because nobody knows what is going to happen".

### Boys vs. girls

We observed fewer gender differences in conceptualization of general and health-related QoL. The main differences between the two genders occurred at the item level, that is, the kind of activities that participants described. For example, boys would describe activities such as playing sports (in particular, soccer and swimming) and computer games while girls would describe a different set of activities, e.g. chatting over the telephone, dancing, shopping, baking cookies, going to movies, etc.

#### Other observations

From the discussion, the participants demonstrated fairly good health knowledge, despite their age. For example, they knew that exercise would make their hearts pump faster. They also knew that reduction in salt intake was necessary for people with their kidney problems. This demonstrates that we have a well-informed group of

participants who are likely to provide reliable information. It was interesting to know that some participants have very negative and not necessarily correct perceptions of healthcare providers. Some comments made during the study included

"(I am) very scared; scared that the doctor say I'd need operation. Very nervous, sad, nervous like anything. My sister always cries, cries, cries. She is a cry baby. Maybe the doctors will take our life away (Laugh). When they do operations, they may kill us. They may cut our kidneys accidentally (Laugh). They will inject us, very painful. The doctor may be a murderer. (Laugh)"

#### Discussion

In this study, we attempted to understand the meaning of general and health-related quality of life from the perspectives of children and adolescents in an Asian country and to evaluate similarities and differences in conceptualization of QoL between Asian and Western children/adolescents. Singapore is a very westernized multi-ethnic Asian society and thus serves as an excellent test case for the purpose of this study. The Singapore healthcare system is benchmarked against the British and the U.S. systems and is rated as the sixth most effective healthcare system in the world [20]. At the same time, traditional medicine and Asian philosophy of health is deeply entrenched in the lives of Singaporeans. If the notion of HROoL in Singaporean children and adolescents were found to be very different from Western children and adolescents, the difference will likely be amplified in other Asian countries. This will then have serious implications for multi-national trials in Asia which incorporates HRQoL as an outcomes measure, not to mention the use of HRQoL in measuring clinical response and disease progression.

The results of this study suggest that there is a 'universal' concept of HRQoL among children and adolescents across the globe. The meaning of general and health-related QoL to Singaporean children and adolescents may be categorised into three broad domains of physical, psychological and social which falls in line with the current widely used definition of HRQoL [21]. The cate-

gories and item meanings within each domain (Table 2) were also strikingly similar to the contents of currently available generic HRQoL instruments for children and adolescents [22], although minor and important differences exist. Hence, our findings suggest an exciting possibility that existing HRQoL instruments for children and adolescent are potentially useful in the Asian population. A primary concern in the use of HRQoL instruments across different cultures is the issue of conceptual equivalence [23]. The issue of whether the two different cultures conceptualize HROoL similarly needs to be addressed before meaningful translation or adaptation of the instruments can take place. This study has thus provided empirical support for cross-cultural adaptation of existing HRQoL instruments for children and adolescents in an Asian country, rather than reinventing the wheel to develop new instruments.

However, we did observe that our study participants assigned different weights to the three dimensions of QoL in consideration of the absence or presence of illness. For example, discussion on general QoL tended to focus on physical aspect of health while discussion of HRQoL centred on psychological aspect. The results suggest that falling ill will have greatest impact on psychological well-being of children and adolescents. Therefore, care-givers of children and adolescent with newly-diagnosed chronic medical conditions should pay careful attention to their psychological well-being.

We have also observed developmental differences between children and adolescents in the conceptualization of QoL and these were similar to other published studies [24, 25]. For example, younger children had limited discussion of subjective dimensions of QoL, emphasizing more on the physical aspects of QoL [24]. In addition, certain words carry different connotations for children and adolescents, e.g. fear and future. The immediate social context surrounding children and adolescents were also found to be different, with the latter having a wider social circle. With respect to the observation that children use positive descriptions more often than adolescents, a related finding was made in an earlier study where Singaporean children were found to have better QoL than adolescents [26]. A possible explanation derived from the focus group discussions was that academic pressure took a greater toll on adolescents than children. Our findings thus support the current practice of developing HRQoL instruments catered for different age groups [13–15]. However, further research is needed to understand the influence of developmental changes on HRQoL. For example, in longitudinal studies evaluating effectiveness of programs or interventions to improve health status, expected improvements in HRQoL may not be observed if changes that have occurred in the transition from childhood to adolescents diminished HROoL. This phenomenon is known as response shift. Sprangers and Schwartz defined response shift as a change in the meaning of one's self-evaluation of a target construct as a result of (a) a change in the respondents' internal standards of measurement, (b) a change in the respondents values or (c) a redefinition of the target construct [27]. Developmental changes may contribute to any of the three components of response shift. Further research is needed to understand the mechanisms by which the process of growing up actually changes an individual's internal standards of measurement, values and conceptualization of QoL.

Compared to developmental differences, gender differences were less important in our study. Boys and girls share highly similar concepts of health and illness. They also engage in many common activities. Hence, different versions of HRQoL instruments for boys and girls are unnecessary, at least in this community-based sample of children and adolescents in an Asian country.

In this study, we have chosen to use the focus group approach to answer our research questions. The focus group methodology has been very useful in providing us with an opportunity to 'hear' the true voice of our target audience. This helped to take out the guess work in developing HRQoL instruments for this demographic subgroup. The merit of this approach lies in its generalizability to the general population since health concepts were directly elicited from the population of interest. In addition, other information that we derived from the focus group, although seemingly unrelated, may be useful in future hypotheses generation.

We recognized the limitations of this study. First, we would have benefited from the expertise of an more experienced moderator. However, as quality of life is a developing research field in this country, people with knowledge in both focus group and QoL are hard to come by. To ensure the highest data quality, our moderator was trained in using an established protocol and mock focus group discussions were performed before the actual study. Second, the sample was selective. We left it to the principals, teachers or persons-incharge to select the participants. This potentially could introduce bias. Nevertheless, we did achieve a good mix in terms of ethnicity and socioeconomic background (based on the type of family dwelling). Third, by including participants of different ethnicities, we are assuming that there are no cultural differences in the conceptualization of HRQoL among these ethnic groups. This assumption needs to be tested in future studies. However, during the course of analysis, we did not observe any blatant differences in the discussion by participants of different ethnicities.

Building on the findings of this study, we would like to propose that future focus group discussion involve younger children (less than 8 years) as there is currently a paucity of QoL instruments suitable for this age group. Younger children are likely to be limited in their ability to express themselves clearly in writing. Hence, the focus group methodology will be very useful in this instance. In addition, it will be useful to involve parents in focus group discussions on QoL so that we can gain a better understanding of the points of departure between parents' and their children's conceptualization of QoL. This would give us a better appreciation of the proxy problem mentioned earlier in the introduction. Furthermore, we would suggest expanding the focus group discussions to children with chronic illnesses. In this study, we have recruited children from the general population, which was necessary because discussions involving only sick children are likely to be biased towards those areas of health that were impaired by their medical conditions. For example, sick children are likely to experience pain and discomfort more than healthy children. In future studies involving sick children, this bias may potentially be reduced by involving groups of sick children representative of the local epidemiology of childhood diseases. Doing so would however incur substantial time and resources, which is not

always feasible. Nevertheless, this is certainly worth pursuing in the future.

#### Conclusion

remarkably similar conceptualization of HRQoL between our study participants and other Western children was found. This suggests an exciting possibility of a 'universal' concept of HRQoL among Asian and Western children and adolescents. However, this needs to be determined in a larger sample in Singapore as well as in other Asian countries which are less westernised compared to Singapore. In addition, minor but important differences were found in the weights that our study participants assigned to the three broad domains of QoL (physical, psychological and social) in the presence or absence of illness. It will be interesting to study if the same differences would be observed in other Asian study samples. Future focus group discussion could also be extended to younger children and parents with children in childhood or adolescence.

# References

- Parsons SK, Mayer DK. Health-related quality of life assessment in hematologic disease. Hematol Oncol Clin N Am 2004; 18(6): 1235–1248, vii–viii.
- Juniper EF. Health-related quality of life in asthma. Curr Opin Pulm Med 1999; 5(2): 105–110.
- 3. Brunner HI, Giannini EH. Health-related quality of life in children with rheumatic diseases. Curr Opin Rheumatol 2003; 15(5): 602–612.
- 4. French DJ, Carroll A, Christie MJ. Health-related quality of life in Australian children with asthma: Lessons for the cross-cultural use of quality of life instruments. Qual Life Res 1998; 7(5): 409–419.
- Eiser C, Morse R. Quality-of-life measures in chronic diseases of childhood. Health Tech Assess 2001; 5(4): 1– 157.
- Morgan DL. Focus Group. Annu Rev Sociol 1996; 22: 129–152
- Cramer JA, Westbrook LE, Devinsky O, Perrine K, Glassman MB, Camfield C. Development of the Quality of Life in Epilepsy Inventory for Adolescents: The QOLIE-AD-48. Epilepsia 1999; 40(8): 1114–1121.
- 8. Young NL, Bradley CS, Blanchette V, et al. Development of a health-related quality of life measure for boys with haemophilia: The Canadian Haemophilia Outcomes Kids

- Life Assessment Tool (CHO-KLAT). Haemophilia 2004; 10(1): 34–43.
- Ravens-Sieberer U, Gosch A, Abel T, et al. European KIDSCREEN Group. Quality of life in children and adolescents: A European public health perspective. Soz Praventivmed 2001; 46(5): 294–302.
- Gerharz EW, Eiser C, Woodhouse CR. Current approaches to assessing the quality of life in children and adolescents. Br J Urol Int 2003; 91(2): 150–154.
- 11. Ikeda D, Morita S, Toyofuku H. Prevention of cold and the harmony of body and mind. In: Humanism and the Art of Medicine A New Century of Health. Malaysia: Soka Gakkai Malaysia, 1999, pp. 11–21.
- Ergil KV. Traditional Chinese medicine. In: Micozzi MS (ed.), Fundamentals of Complementary and Alternative Medicine. New York: Churchill Livingstone, 2001; 303–344.
- Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: First psychometric and content analytical results. Qual Life Res 1998; 7(5): 399–407.
- 14. Riley AW, Forrest CB, Rebok GW, et al. The Child Report Form of the CHIP Child Edition: Reliability and validity. Med Care 2004; 42(3): 221–231.
- 15. Starfield B, Riley AW, Green BF, et al. The adolescent child health and illness profile. A population-based measure of health. Med Care 1995; 33(5): 553–566.
- French DJ, Christie MJ, Sowden AJ. The reproducibility of the Childhood Asthma Questionnaires: Measures of quality of life for children with asthma aged 4–16 years. Qual Life Res 1994; 3(3): 215–224.
- Bergin C, Talley S, Hamer L. Prosocial behaviours of young adolescents: A focus group study. J Adolesc 2003; 26(1): 13–32.
- The European Kidscreen group. Available at http:// www.kidscreen.org/ (Accessed on 4th May 2004).
- Strauss A, Corbin J, Strategies of Inquiry. Grounded theory methodology: An overview. In: Denzin NK, Lincoln YS (eds.) Handbook of Qualitative Research. Thousand Oaks: Sage Publications, 1994, pp. 273–285.

- World Health Organization. The World Health Report 2000 press release: World Health Organization Assesses the World's Health Systems. Available at http://www.who.int/ whr2001/2001/archives/2000/en/press\_release.htm (Accessed on 4th May 2004).
- Fayers PM, Machin D. Quality of Life: Assessment, Analysis and Interpretation. Sussex, UK: Wiley & Sons, 2000
- Rajmil L, Herdman M, Fernandez de Sanmamed MJ, et al. Kidscreen Group. Generic health-related quality of life instruments in children and adolescents: A qualitative analysis of content. J Adolesc Health 2004; 34(1): 37–45.
- Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: The universalist approach. Qual Life Res 1998; 7(4): 323–335.
- Matza LS, Swensen AR, Flood EM, Secnik K, Leidy NK. Assessment of health-related quality of life in children: A review of conceptual, methodological, and regulatory issues. Value Health 2004; 7(1): 79–92.
- 25. Finkelstein JW. Methods, models, and measures of health-related quality of life for children and adolescents. In: Drotar D (ed.), Measuring Health-related Quality of Life in Children and Adolescents: Implications for Research and Practice. Mahwah, NJ: Lawrence Erlbaum Associates, 1998, pp. 39–52.
- Wee HL, Li SC. Reliability and validity KINDL® children generic health-related quality of life questionnaire in an Asian school-based sample. Value Health 2003; 6(3): 183.
- Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: A theoretical model. Soc Sci Med 1999; 48(11): 1507–1515.

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