Evaluating the content validity of the EQ-5D-Y for Chinese children and adolescents

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Abstract

Purpose Health-related quality of life (HRQoL) is key for assessing healthcare outcomes in children and adolescents. The EQ-5D-Y-3 L, adapted from the adult version, is widely used to measure HRQoL among 8–18 year-olds. Despite its effectiveness, concerns about its content validity persist, particularly in Chinese populations. This study evaluates the EQ-5D-Y's content validity in China, focusing on the comprehensiveness, relevance, and comprehensibility of its dimensions among both healthy and diseased children.

Methods A qualitative study was conducted with 30 participants (15 healthy, 15 diseased) aged 8–18 in Shanghai, China. The interviews explored participants' perspectives on the EQ-5D-Y's five dimensions, guided by the World Health Organization's (WHO) definition of health. Data were analyzed using a framework approach, with response challenges identified through an adapted model of response issues.

Results A total of 126 codes were generated, with 87 retained and categorized into three themes: physical ($n = 16$), mental ($n = 30$), and social health ($n = 4$). While responses reflected all five EQ-5D-Y dimensions, social health was notably mentioned as crucial but was absent in the EQ-5D-Y. Participants suggested enhancements in mental health coverage and more specific examples for the current dimensions.

Conclusion The EQ-5D-Y is relevant for assessing HRQoL in Chinese children and adolescents but requires improvements, especially in incorporating social health. Enhancing question clarity and specificity could also improve its effectiveness. These findings guide potential refinements to better capture the health experiences of children.

Plain English Summary

This study examines whether the EQ-5D-Y, a tool used to assess health-related quality of life (HRQoL) in children aged 8–18, accurately reflects the health views of Chinese children and adolescents. Given the concerns about the tool's appropriateness due to cultural differences and its effectiveness in various health situations, assessing the content validity of the EQ-5D-Y

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is crucial. The main question is whether the EQ-5D-Y, effective globally, also suits the Chinese population and captures all key health aspects, particularly those specific to children in China. Our findings indicate that while the EQ-5D-Y effectively measures physical and mental health, it overlooks crucial aspects of social health, which is vital for children's well-being. Participants reported challenges in distinguishing between some health dimensions and recommended the inclusion of more detailed examples for greater clarity. In conclusion, although the EQ-5D-Y performs well in assessing HRQoL among Chinese children and adolescents, it requires improvements, particularly in enhancing its coverage of social health and clarifying the questions. This study provides insights into potential adjustments that could make the EQ-5D-Y more comprehensive and relevant to diverse groups.

Introduction

Health-related quality of life (HRQoL) is an important outcome of health care, reflecting individuals' subjective evaluations of their health [1, 2]. Measuring HRQoL is crucial for understanding patient health [1, 3] and evaluating healthcare interventions [4–6]. The EQ-5D-Y, a preference-based instrument specifically designed for children and adolescents aged 8–18 years, is adapted from the adult HRQoL instrument, the EQ-5D-3 L [7]. It retains similar dimensions and ordinal scaling while modifying dimension headings, labels, and layout for better comprehensibility in children [8]. This version has proven feasible, valid, and reliable across diverse populations, including in China, and is applicable to both healthy and diseased individuals [9–14].

In China, the EQ-5D-Y is increasingly used to assess HRQoL in children and adolescents [13–16]. Although it has shown satisfactory convergent and known-groups validity internationally and in China [13–15, 17], its content validity has yet to be evaluated with input from Chinese youth, which is crucial to ensure it reflects relevant health concepts [18]. Guidelines such as the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) recommend validating instruments in all intended languages to ensure comprehensive coverage of the construct they aim to measure [19, 20].

Concerns also remain about the EQ-5D-Y potentially omitting certain generic or disease-specific health dimensions [21, 22], as well as its applicability to the Chinese general population due to cultural differences [2, 23], similar to issues observed with its adult counterpart, the EQ-5D. Given that the EQ-5D-Y adopts the same five health dimensions as the adult version, it may also share these limitations, underscoring the need to evaluate its content validity from the perspectives of children and adolescents themselves. Three studies [24–26] have directly interviewed children and adolescents regarding the content validity of the EQ-5D-Y. However, two of these studies focused on pediatric and intellectually disabled patients, while the third was conducted in Singapore using the English version of the EQ-5D-Y.

Furthermore, no studies have yet assessed the content validity of the Chinese version of the EQ-5D-Y. Evaluating the EQ-5D-Y's content validity in China is crucial to ensure it effectively measures HRQoL and aligns with Chinese cultural nuances. Validating this instrument will help refine public health policies and healthcare practices, ensuring better resource allocation and patient care. Therefore, this study aimed to assess the content validity of the EQ-5D-Y among both healthy and diseased children and adolescents in China, using the Chinese version of the EQ-5D-Y. By exploring the perspectives of children on the five health dimensions of the EQ-5D-Y, the study seeks to provide insights into the instrument's relevance and comprehensiveness.

Methods

We evaluated the comprehensiveness of the EQ-5D-Y by conducting semi-structured health interviews to determine if its dimensions were naturally reflected in participants' responses. The comprehensibility and relevance of the instrument were discussed by participants at the dimension level. We used a framework adapted from Penton et al.'s 'response issue framework' [27] to analyze these responses and identify any challenges. Our study design and findings adhere to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [28]. We have included this checklist as Appendix 1.

Research team and reflexivity

The interviews were conducted in Chinese by two team members experienced in qualitative research, YS and AS. YS, a master's student, interviewed the healthy participants, while AS, a hospital doctor, interviewed the disease group. Notably, neither interviewer was responsible for the clinical care of any participants. Both YS and AS thoroughly explained the study's objectives, content, and methodology to the participants and their guardians, obtaining written

consent from both. The study received ethical approval from the Institutional Review Board at the School of Public Health, Fudan University (IRB#2022-TYSQ-03–154).

Study design and participants

The study involved children and adolescents aged 8–18 years in Shanghai, China, divided into two groups: healthy individuals and those with specific diseases. Each group consisted of 15 participants, structured into subgroups. The inclusion of healthy children was designed to capture a broad spectrum of health experiences, enabling a comprehensive comparison and contrast of health concepts relevant to both healthy and diseased populations.

The diseased group was recruited from the Children's Medical Center at Renji Hospital, a tertiary facility in Shanghai. Eligibility for participation required: (1) a confirmed clinical diagnosis of anemia, dermatopathy, asthma, congenital heart disease, or leukemia; (2) general wellness adequate for participating in a questionnaire-based survey; (3) informed consent from both the patients and their parents or legal guardians. Each condition had three patients, forming focus groups. Interviews were held individually at the hospital with guardians present, and clinical severity was assessed by the treating clinicians.

The healthy group was recruited from local primary and secondary schools to mirror the age and gender distribution of the diseased group. The healthy participants were interviewed in a combination of group and individual forms: two groups consisted of four participants each, one group had three participants, and four were interviewed individually. These interviews were conducted at schools. Unlike the diseased group, the healthy participants were not accompanied by their guardians during the interviews. All the interviews were conducted face-to-face. There was no relationship established prior to the commencement of the study between the participants and the interviewers. No participants refused to participate or dropped out of the study.

Data collection procedures

Interviewers YS and AS, trained in qualitative interviewing techniques, conducted the sessions after completing four pilot interviews. Each participant first engaged in a semi-structured interview following a protocol and topic guide outlined in Appendix 2. The interviews began with an introduction by the interviewer, an overview of the research background, and warm-up questions to engage participants.

The interview was divided into two main sections. The first section used open-ended questions to explore participants' perceptions of health, asking them to define health,

describe their significant health concerns, and identify potential health challenges. The second section focused on the EQ-5D-Y's descriptive system, where participants completed the simplified Chinese version of the EQ-5D-Y-3 L instrument, evaluated its adequacy, and suggested improvements.

Each session concluded with a summary by the interviewer to confirm the accuracy of the information captured. No field notes were made during or after the interview or focus group. Data saturation was not pursued at this stage of data collection. No repeated interviews were conducted, and all sessions were audio-recorded. Transcripts were not shared with participants for feedback.

Data analysis

The interviews were structured into two parts: one focusing on understanding health and the other on assessing the relevance and comprehensibility of the descriptive system. These sections were analyzed separately using a structured framework approach.

Understanding of health

Transcriptions of all audio records were made verbatim in simplified Chinese. For analyzing health understanding, we adopted the framework analysis method outlined by Ritchie & Spencer [29], which includes five steps: (1) Data familiarization; (2) Identifying a thematic framework; (3) Indexing; (4) Charting; and (5) Mapping and interpretation.

Two trained team members, YD and GZ, conducted the analysis independently. The WHO's definition of health served as a reference, prompting participants to discuss their health from physical, mental, and social perspectives [30], which formed the major themes of our analytical framework. Frameworks are typically structured around core themes and concepts, which are elaborated and subdivided by additional supporting themes and concepts [31]. As a result, following the establishment of the three themes, we commenced the creation of specific concepts within each theme by generating initial codes using inductive coding techniques.

Discrepancies between YD and GZ's findings were discussed face-to-face; unresolved issues were mediated by external researchers ZY and ZM. Once consensus was achieved, they moved to the next transcription, utilizing Nvivo 14 for data management.

After completing the transcription analysis, all relevant codes were exported to an Excel file. Aligning with the EQ-5D-Y's objective to measure health status, codes that did not describe health status outcomes were excluded, such as those describing temporal changes (e.g., temporary weight loss), external events (e.g., accidents), organ-specific or cellular

functions (e.g., immune system performance), external outcomes (e.g., financial impacts), future health impacts (e.g., overall fitness), and non-health domains (e.g., personality traits).

After the filtration process, we grouped codes that shared similar meanings or described the same issue, regardless of positive or negative phrasing. For example, 'I feel happy' and 'I feel unhappy' were consolidated under 'happiness'.

Once the codes were organized and combined into broader concepts, we classified each concept under one of the three predefined WHO themes—physical, mental, or social health—based on their relevance. This organization created a structured framework that effectively captured the multi-dimensional nature of health as experienced by the participants. The framework development was undertaken by GZ and YD. External researchers ZY and ZM reviewed and provided critical feedback on the framework to ensure its robustness and relevance. The entire coding process and the opinions of co-authors are documented in Appendix 3.

Assessment of relevance and comprehensibility

To evaluate the relevance and comprehensibility, we utilized a framework adapted from the existing model of response issues by Penton et al. [27]. This established framework, detailed in Appendix 4, helps minimize bias [20] by focusing on key responsiveness aspects: understanding, interpretation, suitability of response options, and response editing [32]. We tailored the framework to fit our specific needs by retaining only those questions included in our topic guide. In assessing the content validity of the EQ-5D-Y, we compiled a detailed report for each dimension based on participants' comments. Two coders independently recorded these comments and then discussed face-to-face to analyze the information. These discussions continued until a consensus was reached on each dimension. Participants did not provide feedback on the findings.

Results

After presenting the participants, we described the comprehensiveness assessment for which we developed a framework based on the three WHO perspectives on health: physical, mental, and social. For the relevance and comprehensibility assessment, we identified response issues related to the following aspects: comprehension/understanding, interpretation, response option selection, and relevance/comprehensiveness. In the following result section,

the character 'H' refers to participants in the healthy group, while 'HG' denotes the group interviews conducted with healthy participants. The letter 'D' refers to participants in the diseased group.

Participants

A total of 30 participants agreed to take part in the interview, comprising an equal number of patients and healthy children. Demographic information for the participants was provided in Table 1. Half of the participants are female, and half reside in urban areas. The majority of participants are aged between 11 and 15 years ($n = 16$, 53.3%).

Assessment of comprehensiveness

126 codes were generated to summarize participant comments on health. After applying exclusion criteria in the methods section, we removed 39 codes unrelated to health status outcomes. The remaining 87 codes were consolidated based on similar meanings or opposite phrasings of the same concept, resulting in 50 distinct concepts organized under three WHO health themes: physical ($n = 16$), mental ($n = 30$), and social health ($n = 4$). To visualize the results, we presented them in Fig. 1, which illustrates the hierarchical relationship where 'concepts' are nested within 'themes'. All five dimensions of EQ-5D-Y were represented in the figure, with specific details shown in Fig. 1. Notably, the theme of 'social health' was frequently discussed by children but is absent in the EQ-5D-Y dimensions.
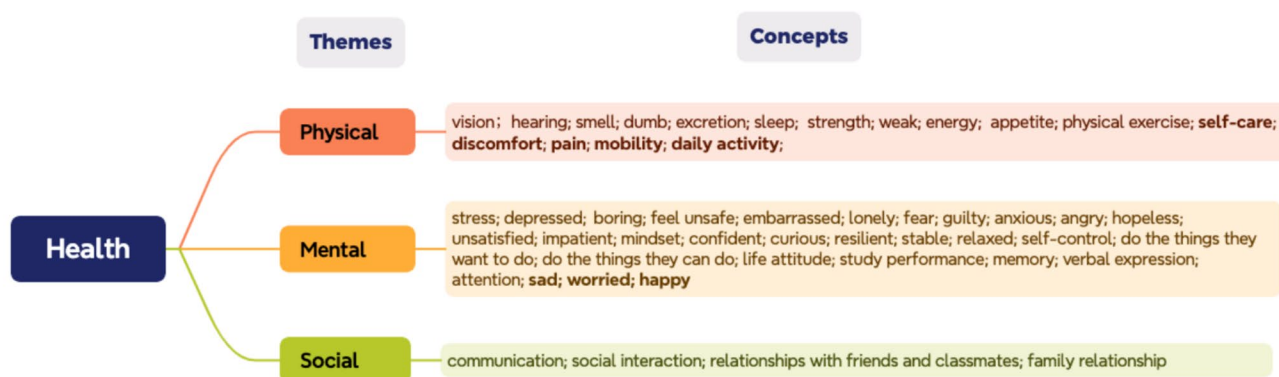
Physical health

When interviewers asked participants about their understanding of health, all 30 participants—whether healthy

Table 1 Socio-demographic characteristics of the sample

Variable	Group	$N = 30$
Gender	Male	16 (53.3%)
	Female	14 (46.7%)
Age (years old)	8–10	8 (26.7%)
	11–15	16 (53.3%)
	16–18	6 (20%)
Participants Category	Healthy	15 (50%)
	Diseased	15 (50%)
*Hukou	Rural	15 (50%)
	Urban	15 (50%)

*Hukou refers to the participants' registered residence, which was categorized as either rural or urban.

Note: The dimensions of the EQ-5D-Y are highlighted in bold.

Fig. 1 Visual representation of identified health concepts within the three WHO health themes

or living with a disease—focused primarily on aspects of physical health. Common associations included the "*absence of disease*" (mentioned by all participants), "*good physical fitness*" (D2, HG4), and a "*strong immune system (not getting ill easily).*" (D6, HG3).

Participants considered physical health to encompass body indicators such as excretion, hearing, and vision, as well as physical functions like strength, energy, and the ability to perform daily activities. This concept of physical health aligns closely with the dimensions of the EQ-5D-Y: discomfort, pain, mobility, daily activities, and self-care. We provided specific evidence from the interviewees to illustrate how they described these concepts.

Discomfort and pain

Discomfort was discussed in two main contexts. For participants with illnesses, discomfort primarily related to symptoms of their condition, such as "*mouth ulcers*" and "*stomach pain.*" (D4) In contrast, participants in the healthy group described discomfort arising from daily activities, like "*sitting for long periods.*" (H4) Nearly half of the participants with illnesses mentioned pain, often linked to their condition: "*constantly feeling pain in a certain part of the body; when in pain, the body hurts.*" (D5) In the healthy group, only two participants mentioned pain—one noting simply that "*health means no pain in the body*" (HG1), and the other referring to "*pain from an injury.*" (H5).

Mobility

In the diseased group, 12 participants emphasized the importance of mobility, particularly the ability to walk: "*Unable to walk*" (D5) and "*I can't walk when I'm in a wheelchair.*" (D11) In the healthy group, mobility was more about the willingness to be active, such as "*going out for a walk or hanging out.*" (HG1, H5).

Self-care

For participants in the diseased group, self-care generally referred to "*whether they faced difficulties in daily living activities.*" (D8) In contrast, for participants in the healthy group, self-care was more about their ability to take care of themselves, such as "*doing household chores and cooking.*" (H6).

Daily activity

In terms of daily life, there was no significant difference between the two groups of participants. They generally considered daily activities to include attending school and engaging in recreational activities: "*I can play with friends every day.*" (D14).

Mental health

As seen in Fig. 1, mental health in this study primarily encompasses three aspects: emotions, cognition, and autonomy. The concepts of 'worried', 'sad', and 'unhappy' mentioned in the EQ-5D-Y are also included in the mental health theme.

In their responses, 'sad' and 'unhappy' mainly referred to feelings and emotions triggered by specific events or situations that caused emotional pain or disappointment, with no significant difference between the two groups. 'Worried' referred to a state of emotional distress about potential negative events or unresolved issues that may occur in the future. For participants in the diseased group, their worries often stemmed from the recurring situations of their illness or concerns about being a burden to others due to their condition. In contrast, participants in the healthy group tended to worry more about unexpected events, school life (grades), and uncertainties regarding the future:

"*In the past, I was actually worried about something—specifically, about becoming hearing impaired.*" (D3).

"*Because in the afternoon, on the way back, I was worried if anything unpredictable or uncertain might happen.*" (H7).

Social health

Our interviews with the children revealed that social health is also very important to them, a component not included in the EQ-5D-Y. It includes the concepts 'good communications with others'; 'social interactions'; 'relationships with friends and classmates', and 'family relationships'. Notable, social health was describe using only 4 concepts.

"*Additionally, the family should be harmonious. If there are constant arguments, I believe that's not healthy.*" (H7).

"*Health also includes strong social skills, such as being friendly and greeting others, as well as frequently making plans to hang out with classmates.*" (HG1).

"*They tend to be isolated, not talkative, have no friends around, and experience unstable emotions.*" (D12).

Assessment of relevance and comprehensibility

We summarized the participants' responses regarding on the adequacy of the descriptive system and their suggestions for improving its relevance and suitability of both EQ-5D-Y-3L and EQ-VAS. The data was organized in an Excel file (Appendix 5), and findings were reported using an adapted framework of response issues [30], as shown in Table 2. Table 2 summarizes the response issues identified in the study related to the EQ-5D-Y instrument. The '-' symbol indicates that no issues were identified for that particular category and dimension, while the numbers represent the number of issues identified. The identified issues include following aspects: comprehension and interpretation, response option selection, and relevance/comprehensiveness.

Comprehension and interpretation

No participant found any terms or phrases unusual or odd. They also did not report any unfamiliarity with the terms or phrases, nor did they struggle with complex sentence structures. However, four issues were identified regarding the overall clarity of the questions, leading to confusion when selecting a response. These issues primarily focused on two aspects: First, some participants mentioned that the questions did not clearly indicate the time frame (HG2, D5, D7), and they were unsure which time period their responses should reflect, even though the questions specifically stated that the reference was 'today'. The second issue was that

Table 2 The number and type of issues identified by participants about EQ-5D-Y-3 L content

Response issue	EQ-5D-Y						EQ-VAS
	Instrument whole	Mobility	Looking after myself	Doing usual activities	Having pain or discomfort	Feeling worried, sad or unhappy	
Comprehension / Understanding							
Odd wording	-	-	-	-	-	-	-
Difficult wording	-	-	-	-	-	-	-
Interpretation							
Difficult interpretation of dimension	4	-	1	3	1	4	3
Narrow interpretation of dimension	-	1	16	14	1	9	-
Response Option Selection							
Missing intermediate response options	2	-	-	-	-	-	-
Inconsistent response	-	-	-	-	-	-	-
Relevance/Comprehensiveness							
Dimension irrelevant	-	-	-	-	-	-	
Dimension unimportant	-	2	5	4	1	3	
Important dimensions missing	15	-	-	-	-	-	
Improvement	9	-	-	-	-	-	14

one child felt that the questions lacked a clear subject, causing further confusion (HG3). They believed that each question is presented as a phrase, such as 'mobility' or 'looking after myself'… Even though the options include a subject, they still find that the phrasal format of the questions can be confusing.

Nine issues were found related to the interpretation of specific dimension. Participants were unsure whether their conditions should be considered as 'having problems'. For example, four issues were identified where participants (HG2, HG3, D13, D15) stated that in the dimension of 'feeling worried, sad, or unhappy', the question did not specify the reason for worried, so they were unsure how to respond. D10 noted that when considering 'looking after myself', because she was hospitalized and didn't need to change clothes, the question about changing clothes didn't apply to her, making it difficult to choose an answer. H13 mentioned that the dimension of 'pain and discomfort' should specify which part of the body is aching. Additionally, HG1, D12 and D4 indicated that some examples given in parentheses included activities they could do and others they could not, leading to uncertainty in their responses.

When asked whether the explanations of each dimension and the examples provided were comprehensive, almost all participants offered suggestions. For the dimension of 'mobility,' HG1 suggested that it should include not only walking but also transportation. For the dimension of 'looking after myself,' nearly all participants suggested adding examples related to preparing food. Other examples mentioned include doing housework, engaging in sports, social interactions, personal hygiene, doing homework, self-discipline, and maintaining good moral character. For the dimension of 'doing usual activities,' the participants believed that important examples to add included socializing, sleeping, eating, and exercising. Other examples mentioned were homework, physical activity, lifestyle habits, labor, hobbies, and recreational activities. Note that much of the examples suggested related both the 'looking after oneself' and 'usual activities'. For the dimension of 'having pain or discomfort,' only H1 suggested including insomnia. In the dimension of 'feeling worried, sad, or unhappy,' the participants recommended adding more emotions, such as anxiety, low self-esteem, anger, fear, curiosity, betrayed, stress, impatience, despair, depression, and suicidal thoughts.

Response option selection

All participants' selected response options matched what they had verbally expressed. However, two participants (D5, H13) felt that there was a gap between two consecutive options. They thought that having only three levels for each question was insufficient and suggested adding more levels, for example, extending it to five levels.

Relevance/comprehensiveness

We marked the dimensions that participants considered unimportant in Table 2. The reasons participants found these dimensions unimportant can be summarized as follows:

1) They do not encounter the situations described in the question in their daily lives. For example, H1 mentioned that he has not encountered people with mobility issues in his daily life, so he considered this dimension unimportant.
2) They have not experienced these situations, or only experienced them temporarily (D7, D8).
3) The participants do not need to engage in those activities. For example, D10 mentioned that because she was hospitalized and could only wear a hospital gown, she had no opportunity to change clothes, so she considered 'looking after myself' unimportant.

When asked if there were any dimensions that could be added, all participants in the healthy group and most of the participants in the diseased group provided suggestions. The most frequently mentioned dimensions were: disease, social relationships, diet, sleep, and economic conditions.

Most participants felt that the instrument was well-designed, comprehensive, and clear, making it easy to understand. However, they also offered the following suggestions: First, they believed that more dimensions related to mental health could be added. Second, they thought some questions were too broad and could be made more specific. Additionally, some participants pointed out that there were overlaps between certain dimensions, such as pain and mobility, which could both be included under usual activities.

Regarding the understanding of the EQ-VAS, no participants reported any issues with clarity. However, three participants expressed uncertainty about how to assign scores, specifically what criteria they should use to rate their health. Most participants suggested improvements to the EQ-VAS, particularly noting that there were too many numbers on the scale, which made it confusing and visually confusing. They recommended keeping only the numbers ending in "0" or "5" on the scale.

Discussion

To assess the content validity of the simplified Chinese version of the EQ-5D-Y-3L, this study conducted semi-structured interviews with both healthy and diseased participants in China. Our analysis revealed that the five dimensions of the EQ-5D-Y generally align with the health themes identified in our framework. We organized 50 identified concepts into three themes based on the WHO's definition of

health, notably highlighting that 'social health,' frequently mentioned by participants, is not explicitly addressed in the instrument. Although the EQ-5D-Y was found easy to understand by all participants, they suggested improvements for clearer questions and recommended including additional dimensions.

The EQ-5D-Y adequately covers physical and mental health dimensions but lacks a specific dimension for social health, which is critical for children. Participants highlighted the importance of effective communication and robust relationships, particularly with family and peers, as essential to their health. Family relationships are crucial, as parent-child conflicts can trigger psychological issues during adolescence [33–36]. Moreover, the ability to connect with peers gains importance as adolescents often seek support from their social circles rather than family. This emphasis on communication, also noted in EQ-TIPS, underscores the need to understand peer relationships' impact on mental health during this developmental stage [37]. Additionally, issues with schoolmates or peer groups are linked to increased mental health risks [38].

A review of children's HRQoL instruments from various countries developed before 2007 [39] showed that health concepts identified by Chinese children align with those recognized internationally. These include physical indicators like vision and hearing, daily functions such as eating and sleeping, cognitive abilities, emotional well-being, and social interactions. Thus, it appears that the responses from the Chinese participants are consistent with international findings.

Figure 1 reveals that the EQ-5D-Y did not capture all concepts mentioned by the participants, especially social factors, which were highlighted by nearly all participants. This might suggest limited content validity of the instrument. However, several contextual elements should be considered. The EQ-5D-Y is purposefully designed as a concise instrument with just five dimensions to focus on essential health aspects, considering the expansive potential scope of quality of life dimensions. This design choice means it naturally omits broader social aspects of quality of life, which, while important, are not the primary focus of this healthcare-oriented instrument. The EuroQol Group's development of the EQ-HWB (Health and Well-being Scale) addresses this gap by integrating more comprehensive quality of life aspects pertinent to both healthcare and social care. Our study's broad invitation for children to express all health-related aspects led to a wider range of identified concepts, many aligning more closely with the EQ-HWB than with the EQ-5D-Y.

When assessing the EQ-5D-Y, all participants understood the questionnaire well. However, many children found it difficult to differentiate between the 'doing usual activities' and 'looking after myself' dimensions, often citing the same activities like eating, household chores, studying, and sleeping for both. This challenge likely arises from children's developing cognitive abilities and limited life experiences, which make it hard for them to distinguish between abstract concepts such as personal health management and routine tasks. Furthermore, there appears to be an inherent overlap between these dimensions, as activities like brushing teeth or getting dressed could fall under both personal care and daily routines. One participant even suggested that the dimensions of 'mobility' and 'looking after myself' should be included under 'doing usual activities.'

This study is the first to explore the content validity of the Chinese version of the EQ-5D-Y. Previous research focused on psychological attributes like feasibility, validity, and reliability [10, 40–42], but content validity had not been assessed in China. We hypothesized that this gap might stem from concerns over children's cognitive and linguistic capabilities in responding to abstract HRQoL questions. However, we found that, when given appropriate prompts, children were capable of expressing their opinions. Even the youngest participant, an eight-year-old boy can communicate effectively, indicating that age does not necessarily restrict a child's ability to articulate themselves. Instead, a child's health status significantly influenced their willingness to share, with those in the diseased group being less forthcoming than their healthy counterparts, likely due to discomfort and poor mental states. Besides, children's understanding of health mirrors that of adults, with significant emphasis on physical and mental health [43]. However, children place a greater focus on social health, particularly concerning family and peer relationships, underscoring the essential role of social support in their overall health.

Our study also has limitations. First, to encourage children to provide more information, we used the three dimensions from the WHO as guiding questions. It may have introduced a degree of leading bias. Secondly, the COVID-19 pandemic may have influenced participants' health perspectives. For example, some participants emphasized the importance of wearing masks and maintaining hygiene, echoing observations from other studies during the same period [20, 44]. Thirdly, although we conducted 30 interviews, exceeding the minimum of 7 recommended by the COSMIN guidelines [45], we regretted not performing a more formal analysis of information saturation. Due to the lack of necessary data, we were unable to present such an analysis in this article. Additionally, focusing specifically on children with chronic conditions could enable more tailored interventions and effectively address care gaps.

Conclusion

This study underscores the importance of assessing the content validity of the EQ-5D-Y to ensure it accurately reflects the experiences and concerns of the target population. While the EQ-5D-Y effectively captures physical and mental health dimensions relevant to children and adolescents, there is potential for improvement. Specifically, incorporating feedback on dimensions like social health could enhance the instrument's comprehensiveness. Despite some issues related to comprehensibility and relevance, participants generally understood the instrument well.

Declarations

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