Developing a Quality of Life Framework from the Perspective of Laypeople: A Qualitative Comparison with the EQ-HWB Framework

Author information:

Guangjie Zhang 1Erasmus MC, Department of Psychiatry, Section Medical Psychology, Rotterdam, the Netherlands

Yifan Ding

1Erasmus MC, Department of Psychiatry, Section Medical Psychology, Rotterdam, the Netherlands

Zhuxin Mao

2University of Antwerp, Centre for Health Economics Research and Modelling Infectious Diseases, Vaccine and Infectious Disease Institute, Antwerp, Belgium.

Zhihao Yang:

1Erasmus MC, Department of Psychiatry, Section Medical Psychology, Rotterdam, the Netherlands

3Health Services Management Department, Guizhou Medical University, Guiyang, China

Nan Luo

4Health Systems and Behavioural Sciences Domain, Saw Swee Hock School of Public Health, National University of Singapore, Singapore

Jan Busschbach

1Erasmus MC, Department of Psychiatry, Section Medical Psychology, Rotterdam, the Netherlands

*Zhihao Yang is the corresponding author: zhihao_yang_cn@126.com

Abstract

Introduction

The EuroQol Health and Well-being instrument (EQ-HWBTM) measures Quality of Life (QoL) outcomes in health, public health, and social care settings. Its conceptual framework is rooted in QoL theory, a multidimensional concept encompassing social, psychological, and physical aspects influenced by cultural factors. The content validity of the EQ-HWB remains unexplored in China. This study addressed this gap through qualitative interviews with Chinese laypeople, uncovering their QoL conceptual framework and comparing it with the EQ-HWB's to evaluate how well it captures its intended outcomes.

Methods

Quota sampling recruited respondents from two regions in China, ensuring diversity in age, gender, education, health conditions, and caregiving experience. Semistructured qualitative interviews were conducted, transcribed verbatim, and analyzed by two coders using a thematic framework approach. The coders refined codes through consensus, removed irrelevant ones based on set criteria, and organized the remaining codes into sub-themes and themes to develop a Chinese QoL conceptual framework. Lastly, this Chinese QoL framework was compared with the EQ-HWB conceptual framework.

Results

We recruited and interviewed 30 respondents, achieving data saturation in the final three interviews. From 221 initial codes, 187 were retained to develop a conceptual framework comprising eight themes: feeling and emotion, cognition, self-identity, coping, physical sensation, relationship, activity, and mindset. This framework largely aligned with the EQ-HWB conceptual framework, except for the absence of the 'mindset' theme.

Conclusion

The conceptual framework of the EQ-HWB is well-represented within the QoL framework. Our findings support the content validity of the EQ-HWB among laypeople in the Chinese context.

Keywords: quality of life; content validity; EQ-HWB; qualitative interview

Introduction

The EQ-HWB is a new instrument designed to measure intervention outcomes in healthcare, public health, and social care for generic populations, patients, and both formal and informal carers [1-4]. Its conceptual framework is based on the QoL framework reported by Wilson and Cleary [1, 5]. The EQ-HWB domains were identified and refined through qualitative reviews of the literature [2, 6]. The item pool was derived from existing questionnaires and item banks commonly used to measure QoL in generic populations, carers, and patients [7]. Items were selected based on psychometric studies [7, 8]. The final EQ-HWB design assesses QoL outcomes using 25 items organized into seven domains: feelings and emotions, cognition, self-identity, coping, physical sensation, relationship, and activity [9, 10].

Previous studies reported that the face validity of EQ-HWB candidate items had been reviewed by the Chinese population [7, 11]. However, the content validity of the EQ-HWB has not yet been comprehensively explored in China. Content validity evaluates how well an instrument captures the targeted aspects it is designed to measure [12]. It is a prerequisite for other forms of validity, such as construct validity and criterion validity [13]. The Consensus-based Standard for the selection of health Measurement Instruments (COSMIN) outlines three criteria for assessing content validity in clinical settings: 'relevance', 'comprehensiveness', and 'comprehensibility'. Comprehensiveness ensures that the conceptual framework of the instrument includes all key concepts from respondents' perspectives [14, 15]. The Food and Drug Administration (FDA) has issued a guideline for developing instruments that apply patient-reported outcome measures, stating that evidence of an instrument's content validity should be appropriate and comprehensive in relation to its intended measurement concept based on qualitative interviews [16].

The structure of the EQ-HWB was developed from a qualitative literature review, but not from qualitative interviews with targeted populations. Concerns exist about whether the content validity of the EQ-HWB can comprehensively and completely capture all relevant aspects of QoL for its target populations. To date, only one study has examined the content validity of the EO-HWB using direct input from target groups, such as patients and informal carers [4]. In this study, while the EQ-HWB demonstrated content validity in the Italian population, two aspects of QoL that were not included in the EQ-HWB conceptual framework were identified, namely, living conditions and the possibility of accessing services. Moreover, previous research has argued that the EO-HWB may not reflect Eastern perspectives on OoL [11], as the EQ-HWB was initially developed based on literature review [6], which was primarily influenced by Western perspectives. Although Chinese stakeholders, like patients and informal caregivers, were involved in the psychometric testing of the EQ-HWB, they did not contribute to the development of the conceptual framework [7, 8]. Therefore, concerns remain that the content validity of the EQ-HWB may be compromised in a Chinese context, since it is unclear whether the instrument accurately reflects Chinese QoL perceptions [17]. Given that cultural factors can shape QoL conceptualizations

[18-20], and considering differences between Western and Eastern cultures, we hypothesize that the Chinese population's QoL will differ from the EQ-HWB conceptual framework. These differences may compromise the content validity of the EQ-HWB in China, or they may prove to be insignificant, with limited impact on its application in the Chinese context.

To address this concerns, this study aimed to: 1) develop a conceptual framework of QoL related to health and well-being in China; 2) compare this QoL framework with the EQ-HWB conceptual framework to examine whether the EQ-HWB reflects Chinese lay perspectives. Notably, this article focuses solely on the comprehensiveness aspect of content validity, while the other two aspects, 'relevance' and 'comprehensibility,' will be addressed in a future separate article.

Methods

Semi-structured, face-to-face qualitative interviews were conducted, following a protocol adapted from a study exploring the EQ-HWB's content validity in an Italian population [4]. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [21].

Research team and reflexivity

The research team comprised six researchers experienced in QoL research and qualitative interviews. GZ conducted all the interviews, refining her skills through two pilot rounds with three respondents each. ZY and ZM reviewed each interview transcript during the pilot stage and verified the quality of the interviews at the end of the pilot study. NL established five criteria for filtering codes during the analysis stage. GZ and YD completed the data analysis and generated an analytical framework. ZY, ZM, and JB reviewed the results and provided feedback on the QoL framework.

Study design

Theoretical framework

The study is based on the theoretical foundation of both inductive and deductive thematic analysis [22].

Participant selection and setting

Using quota sampling, we recruited 30 respondents, ensuring diversity in age, gender, education, medical condition, and registered residence area (rural/urban, known as Hukou). Limits were set for higher education (\leq 12 respondents with university or above) and age (\geq 15 respondents over 45 years). The 30 respondents were divided into three groups: healthy individuals, patients, and informal caregivers, with 10 participants in each group, exceeding the minimum recommended numbers from the COSMIN guideline on assessing content validity [14]. All participants were required to complete a longer than one-hour interview and the EQ-HWB questionnaire independently. After agreeing to participate, respondents were invited to a quiet

public place, like a café or public park, to complete the face-to-face semi-structured qualitative interview.

Data collection

Face-to-face semi-structured qualitative interviews were conducted using a standard topic guide. The topic guide was initially developed in English by QoL experts, then translated into Chinese by GZ and reviewed by ZY and ZM. It was tested during pilot studies and adjusted based on interview results. During the pilot study, respondents found 'poor well-being' difficult to understand, as 'well-being' usually conveys positive meanings in Chinese culture. Therefore, 'QoL' was used instead. The topic guide included an interviewer self-introduction, research background introduction, warm-up questions, and the QoL topic section. The topic guide is provided in Appendix 1.

In the QoL topic section, interviews followed a structured process. Respondents first answered open-ended questions about their perceptions of QoL, then rated their QoL on a 1–10 scale and explained their score. Subsequently, respondents were prompted to identify what poor QoL meant and to provided at least one specific example to illustrate poor QoL. Finally, the interviewer summarized the discussion and asked the respondents whether the summary accurately reflected their perspectives. Ethical approval for this study was granted by Guizhou Medical university (2040-40).

Analysis

After the face-to-face interviews, each interview was transcribed verbatim in simplified Chinese. Data analysis followed Gale's thematic analysis methodology [23], involving five steps: 1) familiarizing with the transcripts, 2) coding using inductive and deductive approaches, 3) developing an analytical framework, 4) charting data into a framework matrix, and 5) interpreting the data. The analysis was conducted in Chinese, with careful attention paid to English translations of sub-themes and themes. All data were imported and analyzed using NVivo 14.

Familiarization and coding

Two coders (GZ and YD) received training in the thematic analysis methodology. They first familiarized themselves with each transcription. Next, they read the transcripts line by line, using codes to extract important information. Both inductive and deductive approaches were applied to generate codes. Deductively, 96 candidate items from the EQ-HWB were used as the initial codebook, reflecting QoL concepts [6]. Inductively, new codes were created for substantive findings beyond the codebook, including: 1) codes that accurately described respondents' quotations and 2) codes that focused on QoL outcomes rather than events or accidents affecting QoL. For example, if a person was unable to sleep due to anxiety, resulting in a very dark complexion, the code would be 'sleep problems' and 'dark complexion'. The two researchers independently coded each transcription and held face-to-face meetings after each interview to discuss and reach consensus on the codes. If disagreements arose, external researchers (ZY and ZM) were consulted. Once consensus was achieved, GZ and YD moved on to the next transcription.

Developed, applied, and charted codes into a QoLconceptual framework

After analyzing all transcriptions, the codes were exported to an Excel file. The research team developed five criteria to exclude codes unsuitable for describing personal QoL. The filter prioritized subjective QoL assessments over objective ones. First, codes related to morality, death, external events like accidents, income, other economic factors, and lifestyle choices were excluded. Second, codes describing changes in outcomes over time were removed. For example, 'longevity' was deleted because it described living, which involves a time factor. Third, codes unable to distinguish between good and poor QoL, such as personality traits, were removed. For instance, the code 'quiet' was deleted because it could not specify whether a person had good or poor QoL. Fourth, codes pertaining to the organ, body system, or cellular level, such as the immune system, were excluded in favor of holistic QoL. Fifth, codes reflecting future rather than present QoL outcomes were excluded. For example, 'health awareness' was deleted as it referred to improving awareness to benefit future outcomes rather than current QoL.

The QoL framework was developed in three stages. First, codes with similar concepts or keywords, whether positive or negative, were grouped into sub-themes. For example, codes like 'I feel happy' and 'I feel unhappy' were grouped under 'happy.' Second, sub-themes were formed by combining codes that described similar outcomes. For example, 'security' and 'safety' were combined into one sub-theme, 'safety.' Finally, sub-themes were categorized into themes, grouping those with similar attributes, aspects, or closely aligned connotations. For instance, sub-themes such as 'happy,' 'anxious,' and 'depressed,' related to feelings or emotions, were grouped under a theme reflecting emotional states. Similarly, sub-themes like 'mobility,' 'vision,' and 'sleeping' were categorized together, as they describe different abilities or functional aspects of daily living. Additionally, sub-themes with aligned connotations based on respondents' quotes were grouped accordingly. For example, 'energetic' was categorized under 'physical sensation,' as respondents described it as a state of vitality and physical energy. Since the multidimensionality of QoL is often expressed in terms of different 'domains,' the 'theme' can be considered equivalent to a 'domain' of OoL.

GZ and YD developed the framework, which was reviewed and finalized by ZY and ZM through consensus.

Compare with the EQ-HWB for testing content validity

We compared our analytical framework with the EQ-HWB conceptual framework at the sub-themes and themes level to reveal the similarities and differences between the two frameworks. Through this comparison, we aimed to determine if the EQ-HWB captures QoL concepts described by Chinese respondents.

Results

Participants

We recruited 30 respondents according to our a priori quats, as outlined in the demographics shown in Table 1.

Table1			
demographic			
Sex	Male	15 (50%)	
	Female	15 (50%)	
Age	<45	15 (50%)	
	>=45	15 (50%)	
Sample	Disease	10 (33.3%)	
characteristic			
	Healthy	10 (33.3%)	
	Informal	10 (33.3%)	
	caregiver		
Region	Guangzhou	22 (73.3%)	
	Harbin	8 (26.7%)	
	Urban	18 (60.0%)	
	Hukou		
	Rural Hukou	12 (40.0%)	
Education	High	11 (36.7%)	
	education		
Note: Urban Huke	ou refers to house	ehold	
registration in urb	an areas; Rural H	Iukou refers to	
household registra	ation in rural area	s; High	
education are univ	versity and above	university;	

QoL Framework

We generated 221 codes summarizing QoL comments and deleted 34 codes, including external impacts (n=11), time-dependent outcomes (n=3), indistinguishable QoL outcomes (n=13), codes pertaining to organs, body systems, or the cellular level (n=5), and codes reflecting future outcomes (n=2). Of the 187 remaining codes, over half (n=97) were developed inductively. We categorized the 187 codes into 57 sub-themes, grouped into eight themes: feeling and emotion, cognition, self-identity, coping, physical sensation, relationship, activity, and mindset. Below, we describe the sub-themes and themes in our analytical framework, focusing on the new findings compared to the EQ-HWB conceptual framework, as shown in Table 2. Respondents' quotes for each sub-theme are provided in Appendix 2.

Feeling and emotion

Feeling and emotion encompassed various positive and negative emotions, which were affected by events, diseases, or accidents. This theme contained the most subthemes in either the Chinese QoL framework or the EQ-HWB framework. It included 18 sub-themes, with four new sub-themes not present in the EQ-HWB framework: 'regret,' 'boring,' 'stress,' and 'emotional abilities.'

• 'Regret,' a negative emotion, arises when the development of events or situations differs from what was expected after a decision is made.

"When she first discovered she had cancer..... She deeply regrets this and......She regrets missing......" (P6)

• 'Stress' was associated with difficulties or dilemmas related to family, academic study, work, relationships, or economic situations. This distress could cause behavioral changes, leading to health problems.

"You have to take care of your own parents while also looking after your children, so the stress is quite significant." (p2)

• 'Boredom' referred to a feeling caused by a lack of engagement in interesting or meaningful activities.

"Being alone at home feels stifling, making me feel very lonely and bored." (p23)

• 'Emotional abilities' referred to the capacity to control, manage, and express emotions, leading to emotional stability and enhanced rational thinking. A person who can effectively control their emotions is likely to maintain emotional stability.

"His emotions are very volatile, suddenly feeling sad, suddenly irritable, suddenly happy, highly fluctuating, and extremely unstable." (p24)

Cognition

The 'cognition' theme aligned with the EQ-HWB framework, sharing the same subthemes: confusion, clear thinking, concentration, and memory. An additional subtheme, 'cognitive impairment,' was identified.

• 'Cognitive impairment' referred to delays in intellectual development. It may manifest as deficits or reduced abilities in learning, understanding, thinking, memory, and problem-solving.

"He is in his thirties or forties, but he behaves like a child.....he just smiles and doesn't take it seriously....." (p28)

Self-identity

The 'self-identity' theme encompassed three sub-themes: dignified/disrespected, self-perception, and an additional sub-theme, 'self-assessment.'

• 'Self-assessment' included both positive and negative aspects of selfevaluation. For example, statements such as: 'I feel disappointed with myself,' 'I lack confidence,' and 'self-denial' reflected negative self-assessments.

".....frequently engaging in self-denial and using various things to invalidate oneself can lead to internal exhaustion." (p21)

"A form of spontaneous self-reflection..... identifying my own shortcomings." (P26)

Coping

'Coping' is defined as the ability to cope with and adapt to changes in external environments, including natural and social environments. This theme contained four sub-themes, with an additional sub-theme—'adaptation'—identified.

• 'Adaptation' refers to the process by which people adjust to external environments and distress.

"Previously......However, after one of his children had an accident and passed away.....started smoking and drinking frequently." (p3) "Peers might have depression.....and might not adapt well to the outside world." (p24)

Physical sensation

Physical sensation was another significant theme, sharing similar concepts with the EQ-HWB framework and including six sub-themes. Three additional sub-themes weakness, appetite, and appearance—were identified in our framework. These new sub-themes described detailed physical sensations impacted by illness or medical treatment.

• 'Weakness' describes a state of physical or mental feebleness, such as experiencing reduced bodily functions after surgery, making walking feel strenuous.

"Before I had the stent placed..... I feel weak and lack energy. Even climbing stairs now leaves me short of breath." (p28)

• 'Appetite' refers to a decrease in appetite or a lack of desire to eat caused by disease or medical treatment.

"..... they don't want to eat, and even if you give them food, they still won't eat." (p22)

• 'Appearance' referred to changes in appearance caused by disease, such as a darkened complexion. It also included spiritual appearance, reflecting a person's positive, vibrant, and energetic state as expressed through their outward appearance.

"Difficulty falling asleep and a very dark complexion." (p19) ".....some impact on his mental outlook. become lazy and lose some of that energy. Gradually, he may lose some of the spirit and vitality......" (p21)

Relationship

'Relationship' was an important aspect of QoL and was frequently mentioned by respondents. This theme shared similar content with the EQ-HWB framework but included three newly identified sub-themes: 'establishing relationships,' 'judgment,' and 'betrayal.'

• 'Establishing relationships' refers to the process of forming and nurturing connections with others, such as workplace relationships.

'I make sure my work doesn't trouble my boss.....only by doing this will it work.' (p3)

• 'Judgment' was created to capture feelings of being judged, discussed, or discriminated against.

"For example, others may discriminate against you....." (p17)

• 'Betrayal' refers to a personal feeling of broken trust or a violated relationship, negatively impacting an individual's QoL.

"..... he started a new phase of life. He felt betrayed and hurt....." (p15)

Activity

The 'Activity' theme illustrated people's capacity to perform basic functions, such as eating, sleeping, walking, and speaking. This theme differs from the EQ-HWB framework, which describes a broader range of activities, including 'physical function,' 'sleep,' and 'diet.'

• The 'Physical function' sub-theme was created to express higher physical capabilities than mobility, such as going to the gym.

"For example, activities like practicing Tai Chi, dancing, and singing....." (p29)

• 'Sleep' was aligned with this theme because it describes the ability to fall asleep or stay asleep.

".....sometimes I feel very tired but can't sleep, which affects my ability to fall asleep." (p29)

• 'Diet' was introduced as a new sub-theme representing the ability to eat food. "......he's quite peculiar. He only eats fish and eggs." (p27)

Mindset

'Mindset' is a newly identified theme for describing QoL and was frequently referenced by respondents. This theme refers to a person's overall way of viewing and approaching things, including their attitudes and perspectives, ultimately achieving a harmonious and peaceful state that unites the interior and exterior aspects of the self. It encompasses three aspects: first, the attitude towards life (life attitude); second, adjusting one's way of thinking about difficulties or challenges when they arise (adjust mindset); and third, influencing those around them by conveying personal emotions or opinions (positive/negative energy).

"Quality of life means that your life...... You should not treat your life as a joke." (p9)

"..... if the disease is severe and beyond one's ability to cope, they are likely to feel very pessimistic and despondent." (p10)

"Once I change my mindset, I no longer mind......when I changed my perspective, it didn't bother me anymore." (p12)

"He tends to blame others.....he often blames others and sometimes even resorts to scolding them." (p15)

Comparison with the EQ-HWB

The two frameworks maintain high consistency in general. The Chinese QoL framework demonstrates a broader scope in structure and content compared to the EQ-HWB conceptual framework. The two frameworks also exhibited significant similarity, with alignment rates of 68% (18/57) for sub-themes and 88% (7/8) for themes.

However, some differences were observed between the two frameworks. First, two sub-themes shared the same concepts but were aligned differently: the sub-theme 'boredom' fell into the 'feeling and emotion' theme in our QoL framework but was part of 'activity' in the EQ-HWB framework. Similarly, the sub-theme 'sleep' was included in the 'activity' theme in our framework but grouped under 'physical sensation' in the EQ-HWB framework. Second, we identified a similar sub-theme, 'autonomy,' as in the original framework, but with broader connotations in our study. Originally, autonomy had a positive meaning, referring to making decisions about one's life even when relying on others, such as doctors. In contrast, our findings also included a negative aspect, 'dependence,' which involved relying on other people's help, ideas, and thoughts, indicating a lack of autonomy in decision-making and independent thinking.

Theme	Sub-theme				
Feeling and	Worry	Overwhelmed	Fear	Anxious	Relax and calm
emotion	Depressed and frustrated	Sad	Satisfaction	Нарру	Safety
	Anger	Regret	Expectation	Hopeless	Boring
	Stressful	Emotion related ability			
Cognition	Confused	Thinking clearly	Concentrate	Memory	Cognitive impairment
Self-identity	Dignitified/Disrespected	Self-assessment	Self-perception		
Coping	Cope	Reliance	Adaption	Control	
Relationship	Betrayal	Support	Get on with people	Socialization	Judgment
	Sense of belonging	Loneliness	Burden	Interpersonal relationship	
Physical sensation	Exhausted	Energetic	Discomfort	Pain	Weakness
	Appetite	Appearance			
Activity	Enjoyable or meaningful activities/role	physical function	Daily activity	Self-care	Diet-what to eat and how to eat
	Mobility	Vision	Verbal expression	Sleep	Hearing
Mindset	Life attitude	Adjust mindset	Negative/positive energy		

Discussion

In this study, we explored the comprehensiveness aspect of the EQ-HWB's content validity. We found a broader QoL framework than the original EQ-HWB conceptual framework, which was almost entirely reflected in our QoL framework, except for the 'hearing' sub-theme. It was omitted by our respondents. Both frameworks collectively describe the concept of QoL as encompassing three main factors: physical, psychological, and social.

The new theme, 'mindset,' was identified, meaning a way of thinking-reflecting a mental framework that shapes how we perceive, interpret, and respond to experiences [24]. It is related to how individuals respond to success and failure and impacts their life direction and sense of life's worth [25-27]. Huang's study showed that a positive mindset correlates with higher life satisfaction and happiness and fewer symptoms like poor sleep, appetite loss, and depression [25], highlighting its closer association with QoL than with health or social care [28-30]. Moreover, 'mindset' reflects how traditional Chinese philosophies and religions, including Confucianism and Daoism, significantly shape Chinese perspectives on health, happiness, and life [31, 32]. Confucianism views happiness as stemming from life satisfaction and social contributions, while Daoism links it to appreciating nature and life, fostering inner peace and harmony [32, 33]. The theme 'mindset' in our framework incorporates aspects of Confucianism and Daoism, as reflected in the sub-themes 'Life Attitude,' 'Adjusting Mindset,' and 'Positive/Negative Energy.' Ding's study also reported that these traditional factors influence Chinese populations' views on health-related quality of life [34].

We anticipate arguments about the similarity between the themes 'mindset' and 'coping.' However, we ultimately decided to keep these two themes separate because their main focuses are distinct. 'Coping' emphasizes an individual's ability to adjust to challenges, focusing on skills and actions. In contrast, 'mindset' highlights a way of thinking, emphasizing perspective rather than action. Although 'mindset' includes the sub-theme 'adjusting mindset,' which resembles 'coping,' the two remain distinct. 'Coping' focuses on actions or behaviors taken to address challenges, while 'adjusting mindset' involves altering one's perspective on the problem and emphasizes mental and emotional regulation in coping, aligning with Western concepts of 'positive coping strategies' [35-38]. This may explain why Chinese respondents tend to describe their QoL in terms of mental and emotional regulation and acknowledge the impact of emotional states on physical health [34]. This also further clarifies why 'mindset' emerged as a distinct theme in our framework.

Sub-themes such as 'emotion control' [39]', 'appetite [34, 39, 40]', 'adaptation (social/environment)' [34, 39]', 'sleep [41]', 'spiritual appearance' [34, 41]', and 'social interaction' [42] are commonly identified by Chinese researchers but overlooked by Western-based QoL instruments. We found that Chinese laypeople use these outcomes to describe their QoL. However, these newly identified sub-themes do

not create new themes, such as 'mindset,' but instead serve as supplements to the existing themes within the QoL framework. This highlights that, when describing QoL, Chinese individuals consider not only personal aspects but also external environmental factors and their relationships with others. Such an approach reflects how the Chinese population perceives QoL holistically.[34, 39, 43].

The first study on the content validity of the EQ-HWB reported that Italian respondents viewed QoL as including 'the presence or absence of diseases,' 'the ability to perform activities,' 'social participation,' 'emotional functioning,' 'living conditions,' and 'the possibility of accessing services.' Although QoL is often seen as culturally grounded [39], our findings did not reveal significant distinctions from the Italian study [4].

More importantly, the QoL conceptual framework from Chinese laypeople aligns not only with the EQ-HWB framework but also with other Western QoL frameworks proposed by scholars [44, 45]. For instance, the WHOOOL assesses OoL as "an individual's perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards, and concerns" [44]. While this definition does not break down into specific themes or sub-themes something typically seen when QoL is operationalized into a questionnaire—it captures both subjective and objective dimensions of OoL. This dual perspective, encompassing both individual and social aspects, aligns with our findings [38, 46, 47]. Several researchers, like Moon et al [48]. or Schalock et al [49] promoted several specific indicators for assessing QoL. These indicators include: 1) emotional wellbeing; 2) interpersonal relations; 3) material well-being; 4) personal development; 5) physical well-being; 6) self-determination; 7) social inclusion; and 8) rights [49]. Our QoL framework aligns well with these criteria, except for 'rights' and 'material wellbeing.' While respondents mentioned aspects of 'material well-being,' such as economic situation, living conditions, and natural environments, during the interviews, these were not included in our framework due to our criteria, which excluded external factors to focus solely on QoL outcomes.

Both the QoL and EQ-HWB frameworks incorporate physical, mental, and social aspects of QoL. Although the two frameworks demonstrate similar core concepts across Western and Eastern populations, differences do exist. These differences are evident in the usage and phrasing of concepts and should be considered when translating and culturally adapting the EQ-HWB. For instance, the sub-theme 'sleep' is categorized under the 'activity' theme in the QoL framework because respondents emphasized their ability to fall asleep. In contrast, the EQ-HWB framework associates 'sleep' with 'energetic' in the 'physical sensations' theme, which places more emphasis on the outcome of poor sleep. Additionally, 'cope with' is commonly associated with distress, challenges, or problems that people actively fight against, rather than with 'coping with daily activity,' as used in Western culture. These differences may help explain why the EQ-HWB factor structure does not fit well

within the Chinese population, indicating a lack of good model fit [8]. More importantly, these differences may require further efforts in translating and adapting the EQ-HWB for use in China.

The EQ-HWB overlooks some aspects of QoL from both Western and Chinese perspectives; however, these omissions are not necessarily significant losses. When developing a QoL instrument, a trade-off in deciding the number of items and dimensions must be considered [50]. For example, 'life attitude' or 'regret' may already be adequately addressed by other sub-themes such as 'enjoyable or meaningful activities/role' and 'cope.'

Limitation

This study is not without limitations. The first limitation concerns the diversity of the sample. The respondents from Harbin were young, relatively healthy, and highly educated individuals. Although the requirements of the quota sampling method were met, the inclusion of patients and elderly participants from Harbin could have provided a broader understanding of their perspectives on QoL. Second, as all patients recruited in this study were from community settings and most had chronic diseases, we suggest that future research consider including hospitalized patients with severe illnesses, particularly those who face significant challenges living independently in the community. Third, although the translation of sub-themes and themes was carefully considered, some sub-themes and one theme were difficult to translate accurately. For example, the sub-theme 正/负能量 was translated into 'Positive/Negative Energy,' and the theme '心态' was translated into 'Mindset.' Moreover, we did not set any criteria for determining data saturation, but we recruited more respondents than the COSMIN recommendation, and similar views on QoL were repeated by the last 10 interviewees. Nevertheless, the final limitation is that we could only determine that the data was saturated subjectively.

Conclusion

The conceptual framework of the EQ-HWB is well-represented within the QoL framework put forward by laypeople in China. This provides supportive evidence for the comprehensiveness of the instrument, a necessary condition for its validity. Although we identified some missing aspects of QoL, these omissions are unlikely to impact the effectiveness of the EQ-HWB. Overall, the study provides evidence supporting the content validity of the EQ-HWB within the Chinese context.

Reference

- 1. Brazier, J., et al., *The EQ-HWB: Overview of the Development of a Measure of Health and Wellbeing and Key Results.* Value Health, 2022. **25**(4): p. 482-491.
- 2. Peasgood, T., et al., What is the best approach to adopt for identifying the domains for a new measure of health, social care and carer-related quality of life to measure quality-adjusted life years? Application to the development of the EQ-HWB? Eur J Health Econ, 2021. **22**(7): p. 1067-1081.

- 3. Norman, R. and J.A. Olsen, *Expanding the Scope of Value for Economic Evaluation: The EQ-HWB*. Value Health, 2022. **25**(4): p. 480-481.
- 4. Masutti, S., et al., *Content validity of the EQ-HWB and EQ-HWB-S in a sample of Italian patients, informal caregivers and members of the general public.* Journal of Patient-Reported Outcomes, 2024. **8**(1): p. 36.
- 5. Wilson, I.B. and P.D. Cleary, *Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes.* Jama, 1995. **273**(1): p. 59-65.
- 6. Mukuria, C., et al., *Qualitative Review on Domains of Quality of Life Important* for Patients, Social Care Users, and Informal Carers to Inform the Development of the EQ-HWB. Value Health, 2022. **25**(4): p. 492-511.
- Carlton, J., et al., *Generation, Selection, and Face Validation of Items for a New Generic Measure of Quality of Life: The EQ-HWB*. Value Health, 2022. 25(4): p. 512-524.
- 8. Peasgood, T., et al., *Developing a New Generic Health and Wellbeing Measure: Psychometric Survey Results for the EQ-HWB.* Value Health, 2022. **25**(4): p. 525-533.
- 9. Kuharić, M., et al., *The measurement properties of the EQ Health and Wellbeing* (EQ-HWB) and EQ Health and Wellbeing Short form (EQ-HWB-S) in Italian Population: A Comparative Study with EQ-5D-5L. Value in Health, 2024.
- 10. Lee, P., et al., *Exploring the Comparability Between EQ-5D and the EQ Health and Wellbeing in the General Australian Population*. Value in Health, 2024.
- 11. Zhang, G., et al., *Can items derived from international literature be used in national quality of life instruments? A qualitative study conceptualising the EQ-HWB in China.* Journal of Patient-Reported Outcomes, 2024. **8**(1): p. 83.
- 12. Fowler Jr, F.J., *Survey research methods*. 2013: Sage publications.
- 13. Zamanzadeh, V., et al., *Details of content validity and objectifying it in instrument development*. Nursing Practice Today, 2014. **1**(3): p. 163-171.
- 14. Terwee, C.B., et al., *COSMIN methodology for assessing the content validity of PROMs–user manual.* Amsterdam: VU University Medical Center, 2018: p. 1159-70.
- 15. Voormolen, D.C., et al., *Development and content validation of the 10-item Well-being instrument (WiX) for use in economic evaluation studies.* Applied Research in Quality of Life, 2024: p. 1-33.
- 16. (FDA), T.F.a.D.A. Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. [cited 2024 17-12-2024]; Available from: <u>https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-reported-outcome-measures-use-medical-product-development-support-labeling-claims</u>.
- 17. the EuroQol group. *EQ-HWB working group*. 2024/12/11]; Available from: <u>https://euroqol.org/information-and-support/euroqol-instruments/instruments-in-development/eq-hwb/</u>.
- 18. Scott, N.W., et al., *The relationship between overall quality of life and its subdimensions was influenced by culture: analysis of an international database.*

Journal of Clinical Epidemiology, 2008. 61(8): p. 788-795.

- Youssef, F. and R. Wong, *Educating Clinicians to Assess Quality of Life in Patients with Chronic Illness*. Home Health Care Management & Practice, 2002. 15(1): p. 20-26.
- 20. Kagawa-Singer, M., G.V. Padilla, and K. Ashing-Giwa, *Health-related quality* of life and culture. Semin Oncol Nurs, 2010. **26**(1): p. 59-67.
- 21. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* Int J Qual Health Care, 2007. **19**(6): p. 349-57.
- 22. Green, J. and N. Thorogood, *Qualitative methods for health research*. 2018.
- Gale, N.K., et al., Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol, 2013. 13: p. 117.
- 24. Crum, A.J., P. Salovey, and S. Achor, *Rethinking stress: the role of mindsets in determining the stress response.* J Pers Soc Psychol, 2013. **104**(4): p. 716-33.
- 25. Huang, Q. and Y. Xie, *Social-demographic correlates of mindset in China*. Chinese Journal of Sociology, 2021. **7**(4): p. 497-513.
- 26. Dweck, C.S., *Mindset: The new psychology of success.* 2006: Random house.
- 27. Zhao, H., et al., *The effect of growth mindset on adolescents' meaning in life: the roles of self-efficacy and gratitude*. Psychology Research and Behavior Management, 2023: p. 4647-4664.
- 28. Zeidman, A., et al., *Association of illness mindsets with health-related quality of life in cancer survivors.* Health Psychology, 2022. **41**(6): p. 389.
- 29. Kwan, Y.H., et al., *Development and calibration of a novel positive mindset item bank to measure health-related quality of life (HRQoL) in Singapore*. Plos one, 2019. **14**(7): p. e0220293.
- 30. Chan, D.W., *Life satisfaction, happiness, and the growth mindset of healthy and unhealthy perfectionists among Hong Kong Chinese gifted students.* Roeper Review, 2012. **34**(4): p. 224-233.
- 31. Chen, Y.c., *Chinese values, health and nursing*. Journal of advanced nursing, 2001. **36**(2): p. 270-273.
- Zeng, H. and S.-P. Guo, "Le": The Chinese subject well-being and the view of happiness in China tradition culture. Acta Psychologica Sinica, 2012. 44(7): p. 986.
- 33. Tsai, D.F.-C., *Eye on religion: confucianism, autonomy and patient care.* Southern Medical Journal, 2006. **99**(6): p. 685-688.
- 34. Ding, Y., et al., *Differences and common ground in the frameworks of healthrelated quality of life in traditional Chinese medicine and modern medicine: a systematic review.* Qual Life Res, 2024. **33**(7): p. 1795-1806.
- 35. Holubova, M., et al., *Quality of life and coping strategies of outpatients with a depressive disorder in maintenance therapy a cross-sectional study.* Neuropsychiatr Dis Treat, 2018. **14**: p. 73-82.
- 36. Schoenmakers, E.C., T.G. van Tilburg, and T. Fokkema, *Problem-focused and emotion-focused coping options and loneliness: how are they related?* Eur J

Ageing, 2015. 12(2): p. 153-161.

- 37. Darlington, A.S., et al., *Coping strategies as determinants of quality of life in stroke patients: a longitudinal study.* Cerebrovasc Dis, 2007. **23**(5-6): p. 401-7.
- Gattino, S., C. Rollero, and N. De Piccoli, *The Influence of Coping Strategies* on *Quality of Life from a Gender Perspective*. Applied Research in Quality of Life, 2015. **10**(4): p. 689-701.
- Mao, Z., et al., Similarities and Differences in Health-Related Quality-of-Life Concepts Between the East and the West: A Qualitative Analysis of the Content of Health-Related Quality-of-Life Measures. Value Health Reg Issues, 2021. 24: p. 96-106.
- 40. Mao, Z., et al., *The unfolding method to explore health-related quality of life constructs in a Chinese general population.* Value in Health, 2021. **24**(6): p. 846-854.
- 41. Mao, Z., et al., *Exploring subjective constructions of health in China: a Q-methodological investigation.* Health Qual Life Outcomes, 2020. **18**(1): p. 165.
- 42. Zhu, W., et al., Valuing Chinese medicine quality of life-11 dimensions (CQ-11D) health states using a discrete choice experiment with survival duration (DCE(TTO)). Health Qual Life Outcomes, 2023. **21**(1): p. 99.
- 43. Lu, L., *A preliminary study on the concept of health among the Chinese*. Counselling Psychology Quarterly, 2002. **15**(2): p. 179-189.
- 44. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med, 1995. **41**(10): p. 1403-9.
- 45. Cummins, R.A., *Moving from the quality of life concept to a theory*. Journal of Intellectual disability research, 2005. **49**(10): p. 699-706.
- 46. Felce, D., *Defining and applying the concept of quality of life*. Journal of Intellectual Disability Research, 1997. **41**(2): p. 126-135.
- 47. Karimi, M. and J. Brazier, *Health, Health-Related Quality of Life, and Quality of Life: What is the Difference?* Pharmacoeconomics, 2016. **34**(7): p. 645-9.
- 48. Moons, P., W. Budts, and S. De Geest, *Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches.* Int J Nurs Stud, 2006. **43**(7): p. 891-901.
- 49. Schalock, R.L., *The concept of quality of life: what we know and do not know.* Journal of intellectual disability research, 2004. **48**(3): p. 203-216.
- 50. Heijdra Suasnabar, J.M., et al., *Exploring the measurement of health related quality of life and broader instruments: A dimensionality analysis.* Soc Sci Med, 2024. **346**: p. 116720.

Appendix- Respondents' quotes

Feeling and emotion

Regret

"When she first discovered she had cancer, it was only the size of a soybean. She said she relied on traditional Chinese medicine and conservative treatments, but the condition eventually worsened. She also underwent chemotherapy, which initially helped, but the cancer later deteriorated again. Now, the cancer cells have spread to her bone marrow, causing pain in various joints. She deeply regrets this and told me that she should have listened to Western medicine. She said she should have started treatment as soon as she found out. She regrets missing the best time for treatment." (P6

Stress

"You have to take care of your own parents while also looking after your children, so the stress is quite significant."(p2)

Boredom

"Not being able to go out affects my mood and mental well-being. Being alone at home feels stifling, making me feel very lonely and bored. Sometimes, it feels worse than death; he often says this kind of torment is unbearable and that it would be better to die than to endure prolonged suffering." (p23)

Emotional abilities

"His emotions are very volatile, suddenly feeling sad, suddenly irritable, suddenly happy, highly fluctuating, and extremely unstable." (p24)

Cognition

'cognition impairment'

"This example is from our village. Look, now he's in his thirties or forties, but he behaves like a child. No matter how you deceive him outside, he just smiles and doesn't take it seriously. Actually, it's just that his mind isn't sharp enough. That's why he didn't study and lacks education. Whatever you say, he just accepts it. He wanders everywhere, and when he's hungry, if someone gives him food, he eats it. If no one feeds him, he goes back home. And even if he goes home, he knows the way back" (p28)

Self-identify

Self-assessment

"For example, frequently engaging in self-denial and using various things to invalidate oneself can lead to internal exhaustion." (p21)

"A form of spontaneous self-reflection, as Confucius mentioned, involves daily self-examination. This type of introspection means that when I face setbacks or failures, my initial thought is not "Why did I fail?" but rather "What caused my failure?" I focus on the reasons behind the failure instead of the failure itself, identifying my own shortcomings." (P26)

Coping

Adaption

"Previously, he didn't drink much and rarely smoked. However, after one of his children had an accident and passed away, it seemed like the impact was too overwhelming for him. He started smoking and drinking frequently." (p3) "Peers may experience lower quality of life in terms of mental well-being due to academic pressure. They may suffer from depression, become irritable, and have poor self-regulation and might not adapt well to the outside world." (p24)

Physical sensation

Weakness

"Before I had the stent placed, I was quite energetic. I could easily climb stairs, and I could even jog up to the 5th floor. I used to live on the 5th floor. Now, after the surgery, I feel weak and lack energy. Even climbing stairs now leaves me short of breath." (p28)

'appetite'

"For example, they don't want to eat, even if you give them food, and even if you give them food, they still won't eat." (p22)

'appearance'

"Difficulty falling asleep and a very dark complexion." (p19) "Perhaps there could still be some impact on his mental outlook. For instance, before he started relying on his parents, when he was in his twenties, he might have been very ambitious and had a youthful vigor and vitality that gave the impression of a young man full of energy. Of course, after he began relying on his parents and didn't actively seek work, he might become lazy and lose some of that energy. Gradually, he may lose some of the spirit and vitality that young people typically have." (p21)

Relationship

'Establishing relationships'

You definitely need to gain recognition from your boss. When you do something, you must focus and be serious about it. I make sure my work doesn't trouble my boss. If you do your job well, those above you won't have

to worry about it. But if you don't do it properly, if there are mistakes here and there, I won't let them criticize me, understand? Only by doing this will it work. (p3)

'Judgment'

"For example, others may discriminate against you, including those close to you who were once very supportive but now, over time, have also started to discriminate against you." (p17)

'Betrayal'

"However, after that person exploited him, he started a new phase of life. He felt betrayed and hurt, having invested a lot of money, time, and energy, but he gained nothing in return." (p15)

Activity

'physical function'

"For example, activities like practicing Tai Chi, dancing, and singing are more enjoyable and preferable." (p29)

'sleep'

"After watching TV and using the phone for too long, sometimes I feel very tired but can't sleep, which affects my ability to fall asleep." (p29)

'diet'

"He just feels nauseous when he sees us eating meat; he's quite peculiar. He only eats fish and eggs." (p27)

Mindset

the attitude towards life

adjust mindset

positive/negative energy

"Quality of life means that your life is your own, and you need to value it. You should not treat your life as a joke." (p9)

"Depending on the severity of the illness, if the disease is severe and beyond one's ability to cope, they are likely to feel very pessimistic and despondent." (p10)

"After falling ill, my mood definitely affects my condition. However, once I let go and stop worrying about other things, everything seems fine. Once I change my mindset, I no longer mind. For example, when I initially felt unwell, I found fault with everything my husband cooked. But later, when I changed my perspective, it didn't bother me anymore." (p12)

"He tends to blame others, attributing his own miserable life to his relatives and siblings. He believes it's their fault for not helping him. He feels they

should assist him with his tasks but don't, and as a result, he often blames others and sometimes even resorts to scolding them." (p15)