Executive Summary

Development of a preference-based instrument: Asian Comparative Study

Jeonghoon Ahn¹, Min-Woo Jo^{1,2}, Sangjin Shin¹, Jooyeon Park¹, Jae Kyung Suh¹, Songhee Cho¹, Minsu Ock², Hyeon-Jeong Lee²

- 1 National Evidence-based Healthcare Collaborating Agency
- 2 Department of preventive medicine, University of Ulsan

□ Background

The EQ-5D is one of the most widely used tools for health-related quality of life (HRQoL). It has an advantage of being easy to conduct as it uses one question for each of the 5 health domains. However, this can also be a disadvantage as there may be areas that cannot be fully assessed using the domains in the tool. Therefore, even people who responded in the EQ-5D that they do not have issues with their health may not necessarily be considered healthy.

Furthermore, there are needs to verify whether the EQ-5D, which was developed in Western society, can accurately evaluate Asians' quality of life and whether there is a need for new domains that can better assess quality of life. Subsequently, we developed an HRQoL measure that is more suitable to Asian countries.

Objective

Our study aims to develop additional domains that are more specific to Asian countries while retaining the existing domains centered on Western society. Using this newly developed tool (EQ-5D with additional domains), we examined the level of health in a general population group and compared results from the original EQ-5D.

☐ Methods

I. Review of HRQoL measurement tools

We searched and reviewed the related tools and literature using the PROQOLID established by MAPI Research Trust. We also reviewed literature related to HRQoL measures in Korea using general medical search engines such as PubMed, KMBASE, KoreaMed, and health research and information centers.

II. Questionnaire development through focus group discussion and consultation with experts

We organized candidate domains that could be included in the preference-based HRQoL instrument after reviewing the HRQoL measures and conducted focus group discussion (FGD) targeting the general public in each participating Asian country. The questionnaire items targeting an actual general population group were determined through consultation with experts.

■. Survey

To examine the practicality of the HRQoL measure, we conducted a preliminary survey of 106 adults aged 19 to 69 in Seoul, Incheon, and Gyeonggi areas and finalized the questionnaire based on this result after revision and modification. Using the new questionnaire, we conducted the survey with nationally representative 1,000 adults aged 19 to 69 (excluding Jeju).

IV. Data analysis

In order to assess the influence of each domain on HRQoL, we performed quantile and linear regression analyses using the visual analog scale (EQ-VAS) as a dependent variable. The logistic quantile regression was conducted with the dependent variable in a binary form to compare each model's explanatory power. After all the surveys in each country are finished, we will compare the obtained results with domains from existing general or preference-based HRQoL tools and results from the participating countries.

Results

- Through survey, we found that 5 domains from the EQ-5D may not fully cover the overall HRQoL domains.
- Vitality, sleep and happiness were important factors for new HRQoL domains. However, since many other factors may exist outside of HRQoL domains, various aspects should be considered when developing a new tool.

I. Review of HRQoL measures

We reviewed 31 HRQoL measures from the PROQOLID DB and KoreaMed DB. The number of questions and the response levels in each tool ranged from 5 to 136 and from 2 to 11, respectively, which demonstrated diversity. The recollection period ranged from "the day of survey" to "the last 30 days," and there were even cases in which no specific period was stated. In the majority of the reviewed tools, the items were listed in the form of questions. Some included the EQ-VAS such as EQ-5D and HAQ, Most surveys could be self-administered, and among the 31 tools, 15D©, AQoL, EQ-5D, HUI®-2, HUI®-3, QWB, and QWB-SA were preference-based.

When the domains included in each tool were classified using 5 domains of the EQ-5D as a standard, the majority of the tools included all 5 domains. The other domains included vision, hearing, speaking, sleep, vitality, sex life, communication, social interaction, role within the family, overall health, feeling, cognition, and self-esteem.

II. Questionnaire development through FGD and consultation with experts

We selected candidate domains and items to be included in the HRQoL measure. In FGD aimed at understanding the awareness of these domains and items, the results were categorized into health-promoting activities, components of health, and thoughts on the EQ-5D. Following the definition of health by the World Health Organization, the importance of physical, mental, and social domains in health was confirmed from the discussion. We

especially verified that items such as vitality in the physical domain, stress in the mental domain, and close relationships and social life in the social domain are important for health. When this was examined relative to the EQ-5D, the EQ-5D had an advantage as it can easily evaluate the level of health, but we found that the domains of the EQ-5D were not sufficient to fully reflect the level of health. Its response scale also had a limitation in reflecting subtle differences in the level of health. Furthermore, with regard to evaluation of one's own level of health or motivation for health promoting activities, we found that people often compare themselves with others or are conscious of others.

In addition, through FGD in each participating Asian country, the key domains were included in the common domains of all participating countries, and the country-specific domains were additionally included in each country. We also established the selection standard and developed the additional domains through consultation with experts and proceeded discussion on question formats and descriptions. Through a series of discussions based on the results from FGD targeting the general public and experts in each participating country, we made a final decision on potential domains for the preference-based HRQoL measure for Asian countries. As a result, vision, hearing, speaking, memory, sleep, vitality, happiness (included only in main study), and close relationship were established as additional measurement domains. The final questionnaire consisted of basic information, HRQoL evaluation, and general items, where general items include occupation, marital status, monthly household income, self-rated health, recent medical use, and current disease condition.

III. Results of the preliminary survey

For self-rated health from the main survey result, 81.1% replied "very good," and 16.0% replied "good." The mean EQ-VAS score for the health state on the day of the survey was 81.99 (standard deviation 11.2).

We examined the average EQ-VAS score according to each category and the respondents' distribution on each domain and level for the EQ-5D's 5

domains and the newly added 7 domains. The result showed that no one responded that they had an extreme problem in all domains, and level 4 (having a serious problem) had a frequency of less than 2% in all domains. Overall, as the level of problem in each domain increased, EQ-VAS score had a tendency to decrease. To examine the influence of each domain on HRQoL, quantile regression analysis was performed using EQ-VAS score as a dependent variable. The quantile regression result showed that the explanatory power of the model using only EQ-5D domains for explanatory variables was 13.6%, and the anxiety/depression domain was found to be statistically significant. In the model using only additional domains as explanatory variables, vitality and close relationships domains showed statistically significant influence. The explanatory power of the model that included all 12 domains increased to 20.0% with the vitality domain showing statistical significance and the memory domain being inter-discipline.

When we asked whether there was any difficulty responding to the questions in order to examine the practicality of the measure, we found that participants generally did not feel difficulty, and only 12 respondents (11.3%) said there was difficulty. When we determined which expression or questions were difficult, most responded that the degree of difference between "slightly (level 2)", "moderately (level 3)", "severely (level 4)" and "extremely (level 5)" was not very clear. As for the questions, some responded that the ambiguity of terms such as "tired or lacking in energy" or "close relationships" and differences regarding evaluation standard may exist.

IV. Results of the actual survey

For self-rated health from the actual survey results, 54.9% responded "very good," 22.3% "excellent," and 20.3% "good." The mean EQ-VAS score regarding the health state on the day of the survey was 80.11 (standard deviation 12.84). Overall, as the level of problem in each domain increased, EQ-VAS score had a tendency to decrease. Among those who did not have problems in the EQ-5D's 5 domains, the number of people who reported problems in vitality was 244 (37.2%), happiness 130 (19.8%), and sleep 71

(10.8%). Among them, the number of people who described their self-rated health from "good (level 3)" to "poor (level 5)" was as high as 76 (11.6%).

Quantile regression using EQ-VAS score as a dependent variable was performed in order to examine the influence of each domain on HRQoL. Pain/discomfort and anxiety/depression demonstrated statistical significance in the model using only EQ-5D domains for explanatory variables. The explanatory power of the model that included all 13 domains increased to 9.0% with the usual activities, pain/discomfort, vision, sleep, and happiness domains showing statistical significance.

The quantile mixed regression model that made the level of independent variables superordinate when the frequency was less than 10 in each domain's response level showed higher practicality of the overall model. Pain/discomfort and anxiety/depression from the EQ-5D domains and vision, sleep, vitality, and happiness from the additional domains showed statistical significance. When the mixed model were adjusted for socio-demographic factors, age and income variables were significant in the quantile regression analysis, while income and education level resulted in statistical significance in the linear regression. Also, in both cases, the explanatory powers increased.

Self-rated health was divided into "not bad" (divided into level 1/2/3 and level 4/5) or "good" (divided into level 1/2 and level 3/4/5), and the logistic quantile regression using them as dependent variables was carried out. In the group that responded that they had no problems in pain/discomfort or anxiety/depression domains, the probabilities of self-rated health being "not bad" or "good" were all significant. Mobility was statistically significant when self-rated health was "good," and usual activities showed significance only when "not bad" self-rated health was used as the dependent variable. The logistic quantile regression from the model including only 5 domains showed that the most meaningful domains reflecting self-rated health were pain/discomfort and anxiety/depression. In a quantile regression of 13 domains, pain/discomfort, anxiety/depression, usual activities, and mobility were found to statistically explain self-rated health. Among the additional 8 domains, the group with vitality had a higher probability of having good

self-rated health and also showed statistical significance. Additionally, sleep and happiness demonstrated significance when "good" self-rated health was used as a dependent variable.

Conclusions

In order to develop an HRQoL measure that is most suitable for Asians, our study established additional domains and developed a common questionnaire for Asian countries through FGDs from each country and discussion between participating countries. Although we were not able to present major comparison of survey results from other Asian countries outside of Korea due to limitations in schedule and finances, we examined the practicality of the questionnaire through the preliminary survey targeting general adults in our country and developed an HRQoL measure for Asians. As we conducted this survey with a general population group in Korea, we reviewed ceiling effect analysis and practicality of the model and found that the 5 domains of the EQ-5D cannot fully cover the general domains of HRQoL. Additionally, self-care among EQ-5D domains did not demonstrate statistical significance in the analysis using EQ-VAS scores or self-rated health as outcome variables. Furthermore, vitality, sleep, and happiness were validated as important factors for new HRQoL domains. Besides this, many factors can exist related to the survey and, therefore, various aspects should be considered when developing the HRQoL measure.

We expect this tool developed specifically for Asian countries could be included in the healthcare policy data such as the Korea National Health and Nutrition Examination Survey and used as a comparative tool between other Asian countries.

Key words

: Health related quality of life (HRQoL), preference-based, Utility, EQ-5D, Visual analog scale (VAS)