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TITLE: The unfolding method to explore health-related quality of life constructs in a Chinese general population

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Highlights:

1. Health-related quality of life (HRQOL) is a complex concept that consists of multiple domains with a diverse list of items that can be included in each domain.

2. While a limited number of studies have investigated which components of HRQOL are considered most important and relevant by general populations for use in evaluating HRQOL, this study addressed this issue across a sample of a general population to explore the conceptualisation of HRQOL.

3. This study argues that it is crucial to be “person-centred” and to pay adequate attention to general populations’ understanding and experience of health.

Summary:

To understand the conceptual constructs of health-related quality of life by using a multidimensional unfolding method.

1 **ABSTRACT**

2 Objectives

3 Health-related quality of life (HRQOL) is a complicated concept that can be measured using
4 multiple health items. Although HRQOL is closely associated with people's subjective
5 assessment of their own health, a limited number of studies have investigated which health
6 items are considered most important and relevant by the general population. Even fewer
7 empirical studies have investigated how HRQOL is understood in non-Western populations.
8 This study used multidimensional unfolding analysis in a Chinese general population to
9 explore the constructs of HRQOL.

10 Methods

11 A scoping review of Chinese generic HRQOL measures and a series of qualitative interviews
12 produced a list of 42 potentially important health items in a Chinese cultural setting. 110
13 Chinese participants in face-to-face interviews ranked the health items from most important
14 to least important. Responses were coded into a rectangular 110*42 matrix and
15 multidimensional unfolding was conducted to analyse participants' preferences for health
16 items.

17 Results

18 It was found that demographic characteristics and one's health condition affected views of
19 HRQOL. Meanwhile, three health items were considered to be most important across the
20 whole sample: sleep quality, body constitution and spiritual appearance.

21 Conclusion

22 This study used a novel approach to explore how people coming from a Chinese cultural
23 setting may perceive HRQOL and which aspects of HRQOL are most important to them. The

study shows that multidimensional unfolding is a feasible approach to assess preferences in a general population. Future studies using this approach are recommended to further explore the constructs of HRQOL in other general populations.

Keywords: China; HRQOL; subjective health status; ranking data; multidimensional scaling; unfolding

1 INTRODUCTION

2 When quantifying ‘health’ in a given group or context, health researchers, clinicians and
3 policymakers are increasingly focused on health-related quality of life (HRQOL), instead of
4 merely looking at traditional outcome indicators, such as mortality or conventional clinical
5 indexes [1,2]. HRQOL is associated with people’s subjective assessment of their own health
6 [3,4]. It is the information to be collected from a “person-perceived” perspective which can
7 reveal people’s subjective evaluation of health [5]. Another characteristic of HRQOL is its
8 multidimensionality [4,6]. Most definitions of HRQOL include multiple domains, such as
9 physical function, mental/psychological well-being, social function, role function and global
10 perceptions of function and well-being, with a diverse list of health items that can be included
11 in each domain [3,7,8].

12 Since HRQOL is a complex, multi-faceted concept and is closely associated with people’s
13 subjective assessment of their own health, it is crucial to include items that are relevant and
14 important to target populations’ subjective health evaluation. Many developers of HRQOL
15 measures have adopted a “top-down” approach to determine the content of a measure [9].
16 Arguably, they have prioritised the views of health professionals, such as clinicians and
17 health researchers, but have paid limited attention to the general population’s or patients’
18 understandings [9]. The widely used HRQOL measures EQ-5D and SF-36, for example, were
19 developed by health professionals when they selected items based on their own expertise
20 [10,11]. However, since non-health professionals (the general population) may understand
21 health differently [12], it may not be appropriate or optimal for health experts to make
22 decisions on behalf of target populations when designing a HRQOL measure. If the designers
23 of HRQOL measures do not pay enough attention to understand how the general population
24 thinks, HRQOL measures may not be able to satisfactorily capture the subjective perceptions

1 of the target population [13]. Problems implicit in the cross-cultural adaption of HRQOL
2 measures may further exaggerate these weaknesses. In recent years, there is a growing
3 awareness that most commonly used HRQOL measures have been developed in Europe or
4 North America and simply translated into various languages for use worldwide. Such a
5 translation process assumes that HRQOL, as a concept, has universal cultural equivalence
6 [14,15]. Without assessing the conceptual equivalence of HRQOL measures in targeting
7 cultures, the translated Western-developed HRQOL measures may fail to include aspects of
8 health that are considered most relevant and important in other cultural settings [16,17].
9 Taking the use of Western HRQOL measures in China for example. Despite a growing trend
10 of using Western HRQOL measures, previous studies have also shown that Chinese people
11 have different views about health compared to Westerners [18,19]. For example, Chinese
12 people were reported to use items comprising concepts from Traditional Chinese Medicine,
13 such as spirits, demons, food and weather to describe health, but such concepts were less
14 common in a Western setting [18]. Consequently, the legitimacy of using Western HRQOL
15 measures in a Chinese cultural setting has been questioned [20].

16 There is limited contemporary research reporting on HRQOL constructs as described by the
17 general population to show which health items are considered most important and relevant by
18 them when describing HRQOL. Even fewer empirical studies have investigated how HRQOL
19 is understood in non-Western populations. This study used multidimensional unfolding,
20 which can deal with ranked preference data, to analyse a Chinese general population's
21 preference for a list of health items, aiming to explore HRQOL constructs in China.

METHODS

Health items for ranking

Our stance is that HRQOL is a culturally relevant concept that therefore cannot be extricated from the cultural context [20]. Therefore, prior to this study, we undertook a scoping review of Chinese generic HRQOL measures and a series of qualitative interviews with Chinese participants from the general population to identify a pool of potentially important health items. In the scoping review, health items that could be used to assess subjective health status were systematically summarised from 12 Chinese-developed HRQOL measures [21-33]. A total number of 19 qualitative interviews investigated how the Chinese general population understand and evaluate health [34]. The scoping review and qualitative interviews jointly identified a draft version of 42 health items capturing various health-related aspects of subjective experiences, feelings or perceptions, both as described in the literature and by the general population, and likely to be of significance in a Chinese cultural setting. The draft items were sent for comment to 10 Chinese people to revise the draft version, eliminate ambiguity and repetition and ensure readability. We used convenience sampling to recruit a number of 10 people, aiming to obtain views from clinicians, health researchers and non-health professionals in a quicker and more cost-effective way. The final version contained 42 health items is displayed in Appendix I.

Participants

To explore the diversity of views, a group of Chinese adult participants with various demographic characteristics and different health status were purposively recruited. The study was considered as potentially cognitively demanding as it required that participants read and comprehend health items as well as make comparisons between them. Therefore, people were

not recruited if they had cognitive problems or had a serious health condition that might limit their ability to complete the study procedures.

Participants were identified and recruited through third-party social groups (such as a Mahjong game club, a care home and a village community). Group organisers were first contacted to help access potential participants; a snowballing approach was also used by asking interviewees to nominate further potential participants. One-to-one interviews were conducted in cities and villages in Southwest China (Chongqing), East China (Shanghai, Jiangsu, Zhejiang) and North China (Beijing and Tianjin).

Data collection procedure

A total number of 110 participants were provided with 42 health items that were individually printed on numbered cards and a printed set of instructions describing how they should sort the items. Participants were first asked to read each item carefully and sort them into three groups labelled most important/least important/the rest. To record these data, a photograph was taken of each participant's card sort.

Participants were then asked to sort the cards onto a grid (See Figure 1) from most important (+5) to least important (-5). The most important item was placed in the rightmost cell and two second most important items on the (+4) column and so on, until all the items were assigned on the grid. This ranking procedure was adapted from the standard sorting process of the Q-methodology [35,36]. Next, participants were asked to compare health items in each column of the grid and to rank them according to importance, displaying all items ranked from the most important one (rank number 1) to the least important one (rank number 42). Instead of asking participants to rank all 42 health items at the same time, with the help of a sort grid, this sorting process was less laborious because it only required participants to rank a limited

number of items each time. Participants were asked to check their ranking results and make any final changes. We took a photograph of their final response.

FIGURE 1 ABOUT HERE

In addition to the ranking procedure, participants were asked to provide general sociodemographic information, including age, gender, level of education and residence place and have completed EQ-5D-5L to provide their health status information.

Analysis

The collected data provided information about participants' preferences for the health items. Unfolding, a technique that is especially useful for analysing such ranked preference data, was used. It was originally proposed by Coombs [37], who located both participants and stimuli simultaneously on a unidimensional model based on each participant's preference for the stimuli, and was later extended to multidimensional cases [38,39]. The main idea of unfolding is to convert participants' preferences for stimuli (health items in this study) into distances in a multidimensional space [40], where each participant can be represented by an "ideal point", plotted in a way that the distance of the ideal point of this participant to the stimuli is closely associated with the participant's preference for the stimuli [40], allowing researchers to visually explore the structure of the dataset. A stimulus that is most preferable to a participant will be placed closer to the participant in the configuration. The stimuli that are placed at the centre of the configuration usually indicate that they are the most preferable among this set of participants, while the stimuli at the outer parts of the configuration are likely to be least preferred by the participants.

Assume that participant i 's rank for stimulus j are treated as proximities (p_{ij}). Unfolding attempts to find coordinates of i and j in a joint space X , so that the distances between the

objects (d_{ij}) in space X agree with the corresponding observed proximities (p_{ij}) as much as possible:

$$f: p_{ij} \rightarrow d_{ij}(X) \quad (1)$$

The particular choice of transformation function f specifies the unfolding model, which can be set as either metric or non-metric.

The most frequently used distance model to calculate d_{ij} in multidimensional unfolding is the Euclidean distance model [40]. Let x_{ik} and y_{jk} denote the coordinate of participant i and stimulus j on dimension k . The Euclidean distance between x_i and y_j can be represented by Equation (2).

$$d_{ij}(X) = [\sum_{k=1}^m (x_{ik} - y_{jk})^2]^{1/2} \quad (2)$$

where m stands for the dimensionality of the space. Since unfolding attempts to find the best approximation of the observed proximities, it aims to minimise the discrepancy between the observed proximities and the corresponding distance between the points. That is, in the following badness-of-fit function, σ_r^2 should be minimised.

$$\sigma_r^2 = \sum_{(i,j)} [f(p_{ij}) - d_{ij}(X)]^2 \quad (3)$$

The square root of σ_r^2 in equation (3) is commonly referred to as raw stress [41]. Because stress value is dependent on the scale of proximity, it is often normalised to be suitable for cross-model comparisons. It can be normalised as follows:

$$\sigma_1^2 = \sigma_1^2(X) = \frac{\sigma_r^2(X)}{\sum d_{ij}^2(X)} = \frac{\sum [f(p_{ij}) - d_{ij}(X)]^2}{\sum d_{ij}^2(X)} \quad (4)$$

The square root of σ_1^2 is known as Stress-1.

The ranked preference data of our study were held in a rectangular 110*42 matrix in which participants are represented by rows and health items are represented by columns. Each row recorded the rank order of health items for a single participant. These sets of rank orders were interpreted as proximities, containing information about dissimilarities (a higher rank of the item indicates that it was less favourable) between an individual participant and health items. The proximity transformation function was set to be ordinal in this study since the input ranking data were ordinal and it was the order of the data, not their ratios, that determined distances in space. Row conditional approach, which only compares proximities within each row, was used, without additionally assuming proximities were comparable across rows. The observed dissimilarities were then converted into Euclidean distances. Having calculated coordinates of the participants and the health items, they were plotted as points in a configuration, where the distance between a participant and a health item represents this participant's preference for the item. To compare solutions with different dimensionality, the model was initially set with a higher dimension then reducing the number of dimensions in further runs from 6 to 1.

The analytic process was conducted by PREFSCAL within SPSS Statistics 22.

RESULTS

The demographic and health status information of the 110 participants is presented in Table 1.

TABLE 1 ABOUT HERE

Descriptive statistics

Figure 2 presents the frequency distribution of each health item in the three importance categories ("most important", "least important" and "the rest") as well as the mean rank of

each health item. Among the 42 items, body constitution, sleep, spiritual appearance, self-care and life attitude were most likely to be valued by the participants as most important, as they were most likely to be assigned to the “most important” category by the majority of the participants (>60%) and were with the smallest ranking scores. In contrast, adaptability to weather changes, fear, loneliness, sex life and ability to make decisions were most frequently to be regarded as least important.

FIGURE 2 ABOUT HERE

The multidimensional unfolding solution

A two-dimensional solution for this dataset was accepted. This was because, on the one hand, it can provide more information about the structure of the dataset than a one-dimensional solution (the one-dimensional solution can be found in Appendix II); on the other hand, a higher-dimension model did not fit the data substantially better. The normalised stress value (see Equation 4) was 0.13 in a 2-dimensional model, 0.12 in a 3-dimensional model, 0.11 in a 4-dimensional mode, 0.10 in a 5-dimensional model and 0.10 in a 6-dimensional model. It shows that increasing dimensionality of the model did not considerably decrease the stress value. Besides, since unfolding intends to compress the complexity of data and to produce information more easily, constituting a lower-dimensional space is usually more favourable. A two-dimensional solution is also considered to be sufficient enough for interpretation in most cases [40,42].

There have been no “rules of thumb” for stress values for multidimensional unfolding in the literature [43]. Some researchers proposed that one way to benchmark stress values is to calculate the stress value expected for random data [44], because there should be no real structure within a set of random data, such data should produce the worst value of stress.

Following this idea, 15 matrices, each consisting of 110 cases of 42 randomly ranked items, were generated and analysed by PREFSCAL program. The mean stress value of the 2-dimensional solution for the randomly-generated data was 0.22 (with a standard deviation of 0.001), which was significantly larger than the observed stress value (0.13) of the 2-dimensional solution for the collected preference data in this study. Therefore, the stress value of the 2-dimensional solution of the unfolding model was considered to be acceptable. Figure 3 displays a 2-dimensional representation of the joint space shared by the 42 health items and 110 participants. For the 42 health items, Dimension I (in the horizontal direction in Figure 3) seems to discriminate between endogenous and exogenous health items. At the extreme of the right-hand side, most of the items were about one's physical health conditions, such as body weight and colour of the face. Health items about one's mental senses, such as depression and anxiety, were also located on the right-hand side in the figure, with positive values. On the left-hand side, the health items relating to one's external social wellbeing such as social support, morality, adaptability to the social environment and social relations, received the lowest (negative) scores. Dimension II (in the vertical direction in Figure 3) appears to differentiate between function indicators and symptoms/feelings. On top of the figure, health items were most likely to be related to functional abilities. Cognitive function, such as ability to response and ability to concentrate as well as physical function, such as ability to hear, ability to see and ability to conduct usual activities were found at the extreme (positive) end of the vertical line. While at the bottom of the graph, most of the health items were about one's emotional experiences. For example, loneliness, fear and anger were found to hold lowest (negative) values in the vertical dimension.

In Figure 3, it seemed that health items that are in a similar health attribute were plotted close to each other on the configuration. For example, self-care, mobility, vision, hearing and usual activities tended to be clustered together and it appeared to be that they were all relating to one's ability in doing physical activities. Health items on the graph could then be roughly clustered into six categories: Physical function, Physical sense, Emotional experiences, Mind-frame, Social wellbeing and Cognitive function based on our interpretation. Further, it was also shown that for clusters that tended to be more relevant to each other were placed closer on the configuration: items relating to function abilities (cognitive function and physical function) were near to each other on the graph; items that were about physical health (physical function and physical senses) appeared to be close; physical senses and emotional experiences can be considered both as symptoms and were located next to each other; the same applied to the mind-frame cluster and the social wellbeing cluster.

FIGURE 3 ABOUT HERE

The 110 participants were spread in the middle of the configuration. When participants were divided into four groups (in Quadrant I, II, III and IV, respectively), as it is shown in Table 2, participants that were plotted in Quadrant IV were with the lowest average age and they were close to items about mental health, which suggested that younger participants tended to emphasise mental health more frequently. It was also found that elder participants were more likely to emphasise cognitive function items and physical health items, as participants placed in Quadrant I and II were with highest average ages. Also, social wellbeing and mind-frame aspects were likely to be emphasised by participants who were located in the Quadrant III and whose average self-rated scores were the highest compared to that of other Quadrants.

TABLE 2 ABOUT HERE

Three health items (body constitution, sleep quality and spiritual appearance) were in the middle of the configuration which indicated that they seemed to be rated as most important across the whole sample. On the other hand, items including adaptability to weather changes, family medical history, dependence on medicine, the colour of the face, body weight, fear, loneliness and sex were far from the origin, where most participants were allocated, therefore seemed to be less important to the group of participants.

DISCUSSION

Our study highlights the difficulty in defining and measuring HRQOL. The multidimensional unfolding analysis indicates that participants had distinct preferences in choosing which health items were more important than others. Because of different demographic characteristics and health status, people tend to have various preferences for health items. For example, our study shows that younger individuals were more likely to be aware of mental problems, while elder people were more likely to highlight the importance of physical and cognitive abilities. This may be for several reasons. For example, younger people may be more aware of mental health due to greater awareness of such issues within popular culture, or reduced stigma around mental health. Or perhaps, because elder people tend to have more physical and cognitive function problems and such health concerns may be more salient, while the younger who tend to be in better physical health condition may be more aware of their mental wellbeing. Elder participants were also more likely to consider social wellbeing and mind-frame as most important than young individuals. This may be because the elderly tend to have more experiences in appreciating the impact of social relations and hope to be well involved in social communities more [45]. Our study also shows that one's health status can influence one's interpretation of health, participants with a lower self-rated score tended to have a strong preference for those endogenous health items, including those about physical

senses, physical function and emotional experiences, while participants with a higher self-rated score were more likely to emphasise exogenous health items such as social wellbeing and life attitude. It may be because people in poorer health status are more likely to be aware of the significant function limitations caused by health issues or negative feelings/sensations thus emphasise those items when appraising health. While, in contrast, people in better health status are less likely to be troubled by those functional problems or negative experiences. They tend to think about health with a higher expectation, thus may define health more positively and consider wellbeing items as more important.

Our study, therefore, indicates that when measuring HRQOL, it is essential to listen to the target populations to understand the attributes of health that are most important and relevant to be measured. HRQOL, unlike more objective health indicators, refers to individuals' perceptions of their health status and is by definition open to the challenges of subjectivity [46]. Undertaking person-centred studies appears to be a necessary and informative precondition to improving the description and measurement of HRQOL. Since only a limited number of empirical studies have investigated understandings of HRQOL from the perspective of general populations or patients, this study recommends further exploration of the constructs of HRQOL in other populations.

Apart from exploring HRQOL constructs in a general population, our study also emphasises the culturally relevant feature of HRQOL. The multidimensional unfolding analysis showed that body constitution, sleep quality and spiritual appearance were rated to be the most important health items across the whole sample of Chinese participants. Except for sleep quality, these could be considered as "Chinese-specific" concepts. Spirit, in Chinese "神", is a central notion in traditional Chinese knowledge and can be narrowly referred to the external manifestation of one's life activities [47], including people's consciousness, mind, thoughts

1 and/or vitality, emphasising on different meanings in different contexts. This term was
2 adapted to “spiritual appearance” as a health item and was highly valued in this study. It
3 indicates that “spirit” could be an important aspect in evaluating health among Chinese
4 general populations. Body constitution is another term that might be specific to Chinese
5 culture. The concept is believed to be introduced by Traditional Chinese Medicine theory.
6 International Classification of Diseases 11th (Traditional Medicine chapter) defines body
7 constitutions as “the characteristics of an individual, including structural and functional
8 characteristics, temperament, ability to adapt to environmental changes, or susceptibility to
9 various health conditions” [48]. Previous studies reported that this term was well recognised
10 in Chinese communities and might be a useful indicator for self-rating health among Chinese
11 general populations [49,50]. This study also shows that this “Chinese-specific” concept
12 seems to be well understood and accepted as an important item to assess health by a Chinese
13 general population.

14 As it was found that health items including spiritual appearance, sleep quality and body
15 constitution were agreed to be essential in describing health. They may be a common core set
16 of health items that are of relevance to Chinese people but are not included in those widely
17 used HRQOL measures, such as EQ-5D. The study, therefore, presents cultural differences in
18 measuring health between China and the West. In the context of the widespread application
19 of Western-developed HRQOL measures worldwide, health researchers are likely to take it
20 for granted that those commonly used HRQOL measures are always appropriate for use
21 globally. This study presents cultural differences in defining and measuring health and argues
22 that subjective understandings of health are structured in a certain cultural setting. It delivers
23 an important message that Western-developed HRQOL measures may not be comprehensive
24 for use in a significantly different cultural setting.

LIMITATIONS

This study was more of a qualitative study and its nature was exploratory. Despite that the multidimensional unfolding technique provided an interpretable solution, this study can be criticised due to the subjective role of the researcher in describing the output of the unfolding analysis. The processes of determining numbers of dimension, interpreting Dimension I/II and categorising health items on the configuration inevitably involved our subjective understanding.

Although the process of generating health items and exploring HRQOL constructs was conducted in a systematic manner, we were tentative in stating that the identified health items were free from criticism. Some health items, such as colour of the face and appearance, may be captured by function-related items and may be considered less useful in advising decision-making in a clinical setting. The current research was not able to respond to such problems. The internal relationships, such as the cause-effect relationship, among various health items in the HRQOL constructs needs further research.

The majority of the participants in this study were in relatively good health status and/or with a high education degree and their views may largely affect the results. Therefore, the sample may not well represent the Chinese population as a whole. Future studies with a more representative sample are needed to further justify the findings.

CONCLUSION

This study used a novel approach to explore the subjective understandings of HRQOL in a Chinese general population. It shows demographic characteristics and health status can affect people's views of HRQOL. It helps to identify health items, including those Chinese-specific items, which seem to be most important and relevant in assessing subjective health in a

Chinese cultural setting, to show HRQOL is a culturally relevant concept. This study also implies that multidimensional unfolding is a feasible approach to assess preferences structures in a general population. Future studies using this approach are recommended to further explore the constructs of HRQOL in other populations.

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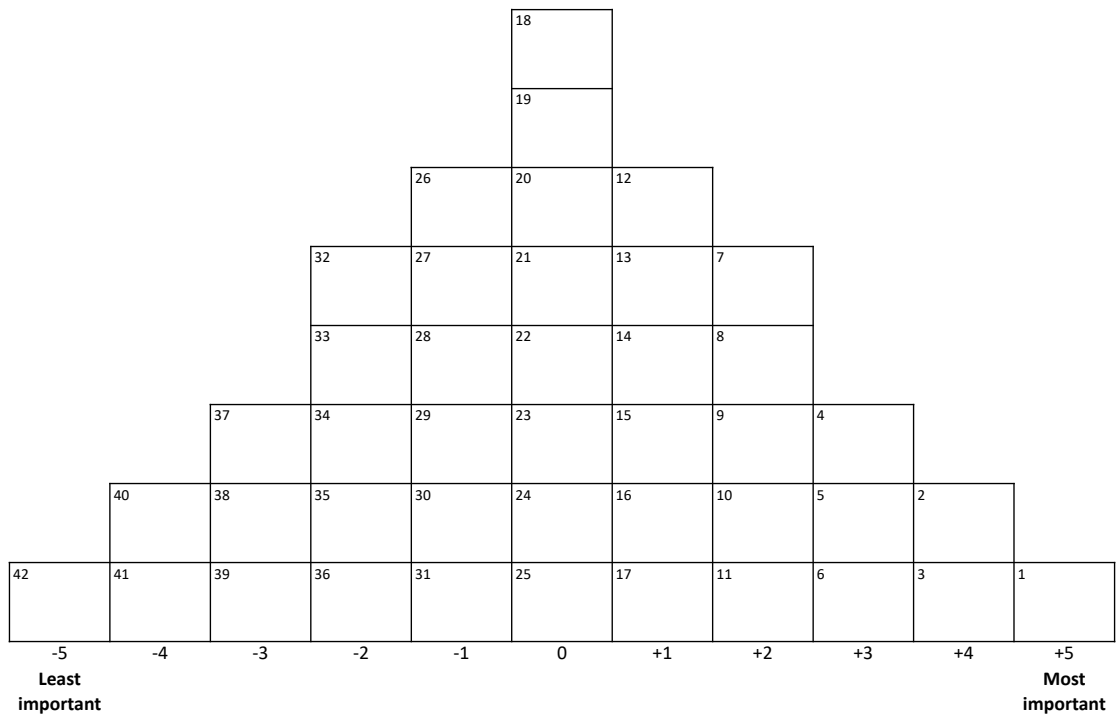


Figure 1 The grid for the ranking procedure

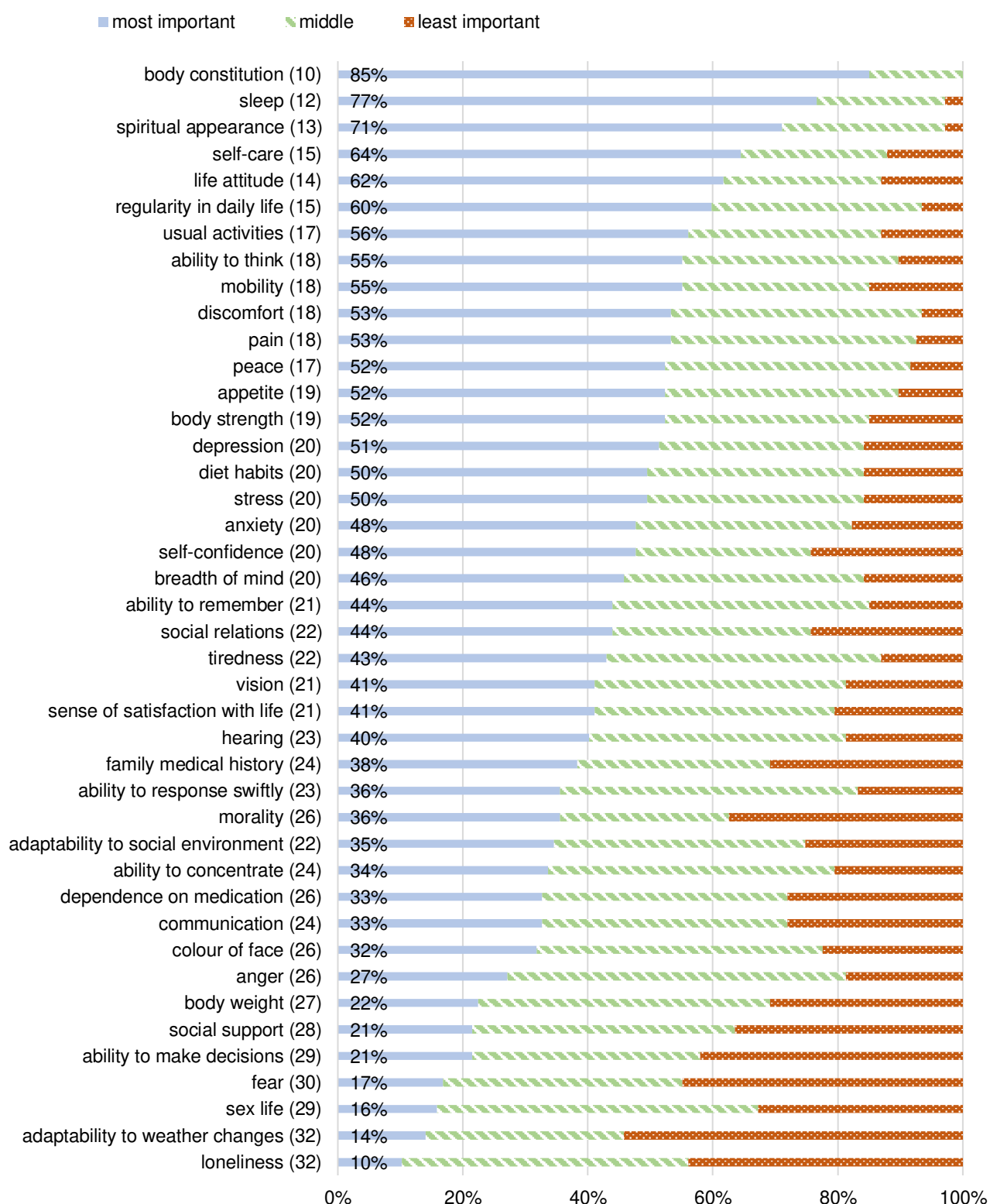


Figure 2 The frequency distribution* of each health item in the three importance categories and the mean rank of each health item (as shown in brackets)**

* The three importance categories information was only captured in 107 participants' interviews.

** The mean rank (adding all participants' ranks for a health item then dividing the total number by 110) is shown in brackets besides each health item.

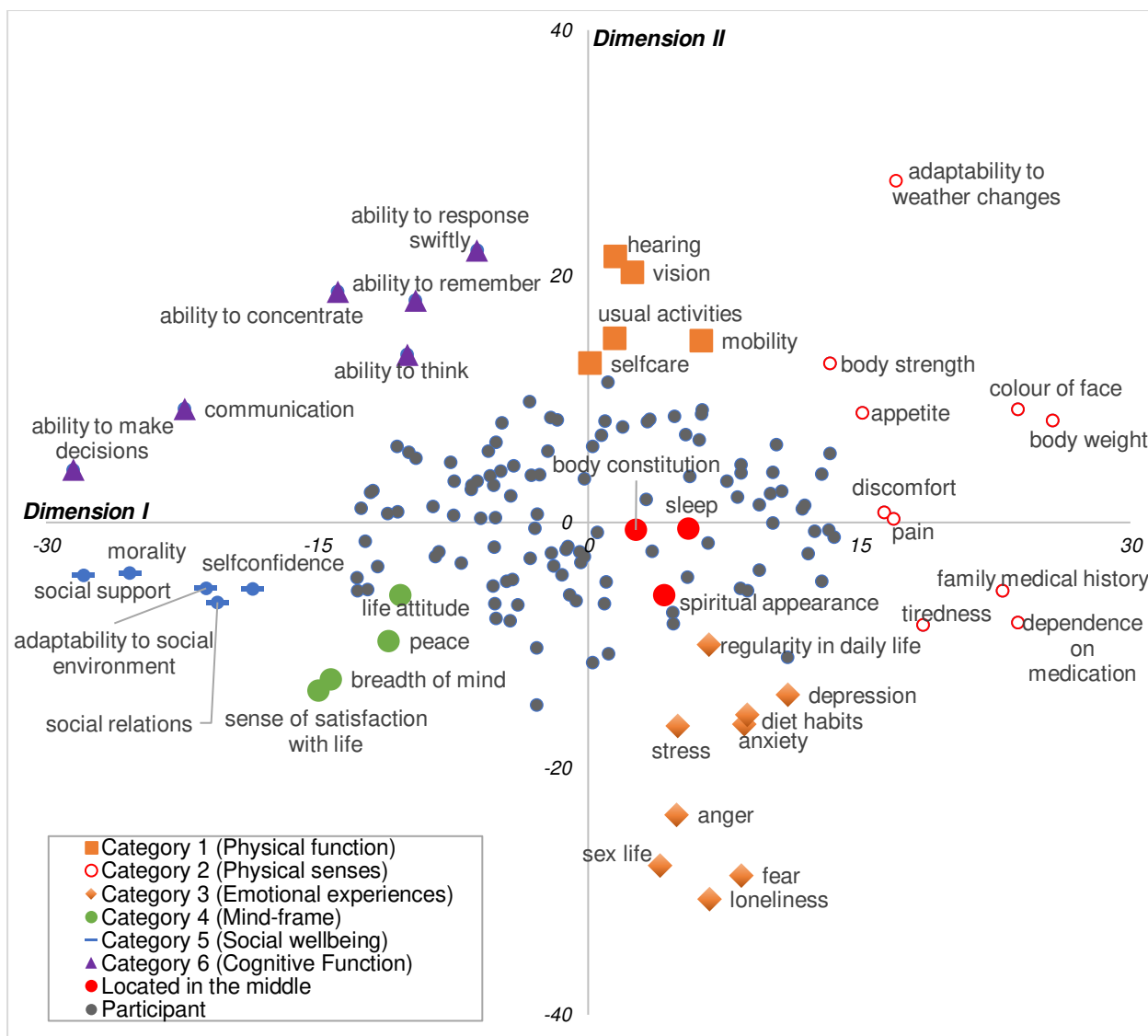


Figure 3 Joint plot for 110 participants' preference ranking of 42 health items (Categories were labelled based on the content of health items clustered as interpreted by authors)

<hr/>		
Gender		
	Male	57 (52%)
	Female	53 (48%)
Age		
	<40	45 (41%)
	40-60	36 (33%)
	60+	33 (30%)
Mean age		46
Education background		
	Under high school	20 (18%)
	High school	14 (13%)
	Vocational secondary school	15 (14%)
	College	18 (16%)
	University	42 (38%)
Self-rating health state using EQ-5D		
	11111	42 (38%)
	11121	16 (15%)
	11112	15 (14%)
	11122	14 (13%)
Self-rated health score (EQ-VAS)		
	80-100	69 (63%)
	60-80	35 (32%)
	<60	5 (5%)
Mean EQ-VAS		77.5
Residence place		
	City	63 (57%)
	Non-city	47 (43%)
<hr/>		

2 **Table 1 Demographic and health status information for participants (n=110) (1 participant's EQ-5D data**
3 **was missing)**

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	Average age	Average self-rated score	Clusters of health items within the Quadrant
Quadrant I	46 years	76.5	physical function and physical sense
Quadrant II	53 years	78.3	cognitive function
Quadrant III	42 years	78.5	social wellbeing and mind-frame
Quadrant IV	38 years	75.8	emotional experiences and physical senses

2 **Table 2 Characteristics of participants in Four Quadrants**

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