

Original Article

Ensuring Cultural and Cognitive Integrity in Instrument Translation: Quality of Life Index for Japanese Cancer Patients

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ABSTRACT

Objective: The objective of this paper is to provide a practical illustration of methods useful for translating and testing questionnaire instruments for nursing and healthcare to ensure reliability, validity, and appropriateness for the target culture.

Methods: We present the process used to create the Japanese version of a well-established quality of life (QOL) instrument, originally developed in American English. The Ferrans and Powers Quality of Life Index (QLI)-Cancer Version III was translated into Japanese by a team of bilingual translators and tested using an iterative process involving cognitive interviewing with monolingual Japanese cancer patients. **Results:** Discussions among the translation team made it possible to find and resolve linguistic, cultural, and practical issues regarding the

translation. Problems stemming from question interpretation and information retrieval were resolved through the cognitive interviewing process. One problem related to response editing could not be remedied with altered phrasing, namely a question referring to the respondents' sex lives. This item was retained in the Japanese version of the QLI as an indispensable component of QOL, particularly in a healthcare context. **Conclusions:** The final Japanese version captured the intended meaning of the original, and also was culturally appropriate and clearly understood by Japanese cancer patients.

Key words: Cancer patients, cognitive interviewing, quality of life

Introduction

In oncology, measuring the quality of life (QOL) helps us to understand the impact of cancer and its treatment from a patient-centered perspective and is thus essential to make informed clinical decisions. Although many

instruments measuring health-related QOL have been developed for cancer patients, the Ferrans and Powers Quality of Life Index (QLI) is unique from these other

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instruments in its approach to measuring QOL, with its focus on satisfaction with the aspects of life that matter most to the individual.^[1] Although more than 400 studies using the QLI have been published till date,^[2] and the QLI has been translated into more than 20 languages, there was no Japanese version until our research team decided to take on this task. Other instruments already exist in Japanese for assessing the QOL of cancer patients; however, those instruments assess the QOL very differently from the Ferrans and Powers QLI. One addresses symptoms specific to prostate cancer and treatment,^[3] another measure functional status and symptoms for palliative care,^[4] and one focuses on cancer survivors, assessing a variety of topics, such as symptoms, psychological distress from illness and treatment, fears of cancer recurrence, and participation in religious activities.^[5] In contrast, the QLI provides a very patient-centered approach, by measuring satisfaction with various aspects of life and weighing the importance of those aspects for the individual. The QLI also has been used across the spectrum of cancer care, from initial diagnosis, treatment, survivorship, and palliative and end-of-life care. Taking these facts into consideration, we hypothesized that the QLI would be a highly suitable instrument for the measurement of subjective well-being in Japanese people.

This article provides a practical illustration of methods useful for translating and testing instruments for nursing and healthcare. According to the Census Bureau Guidelines for the Translation of Data Collection Instruments and Supporting Materials, three types of equivalence are essential for achieving a high-quality translation: (1) semantic equivalence—the meaning of the source text is accurately conveyed; (2) conceptual equivalence—the concepts of the source text are accurately conveyed; and (3) normative equivalence—the translated text takes into account the societal rules of the target culture.^[6] Thus, when a health-related measure is translated from the source language into a target language, cultural values regarding health need to be taken into account. It is vitally important to ensure the appropriateness of a measure at the pragmatic as well as the linguistic level. Therefore, we conducted our translation of the QLI following these steps: First, to create the initial translation we used the committee approach, which is a team-based translation method frequently used in questionnaire translation; second, we used cognitive interviewing with a group of Japanese cancer patients to screen for possible problems, and test corrected wording; and finally, we evaluated the patients' responses to the Japanese QLI based on the results of a questionnaire survey. In this article, we will describe the initial two steps by which our research team produced the translation of the QLI, utilizing methods to

ensure its cultural appropriateness, as well as semantic and conceptual accuracy.

Conceptual basis for quality of life

The World Health Organization^[7] defined QOL as “an individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to goals, expectations, standards, and concerns” (p. 1405). Therefore, QOL can be considered as a largely subjective concept, and many circumstances (personal, cultural, material, and emotional) all contribute to an individual's perception of his/her QOL. Thus, when translating an instrument to measure QOL into Japanese, it is imperative to consider the cultural context and value systems of Japanese people because of the close relationship between language and cultural norms and social practices.

In the QLI, QOL is conceptualized as “a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.”^[8] While the majority of health-related QOL instruments focus mainly on the more objective measures of symptoms and function in assessing patient QOL, the QLI measures overall QOL, which consists of four domains: health and functioning, psychological/spiritual, social and economic, and family.^[9] The comprehensive set of items in the QLI provides an estimate of QOL as perceived by the patients themselves.^[1,10,11] The QLI Cancer Version consists of two sections, each with 33 parallel items, answered on a Likert-type scale to measure both satisfaction and importance of various aspects of life. Respondents select the most appropriate answer for each item from the six options which indicate ranges of being very dissatisfied to very satisfied or from very unimportant to very important. The importance ratings are used to weight the satisfaction responses,^[10] so that the QLI measures subjective well-being regarding satisfaction with the aspects of life that are most important to the respondent, consistent with the definition.

Translation by committee

The committee approach is increasingly recommended as a more “comprehensive and collaborative” method of translation than either the solo or the forward-backward translation approach. It is preferred because it more accurately captures the culture-specific attributes of the target population.^[12] Rather than relying on the skills of a single translator, the committee approach brings together the combined skills of some people who are experts in the subject matter, language, data collection, and so on to collectively produce a translation.^[12] Generally each member of the team independently translates from the original language to the target language, and then the group

discusses differences until a consensus is reached to create a reconciled translation reflecting the best thinking of the group. In a study describing the comprehensive use of multiple methods to translate psychosocial measures from English into Hindi,^[13] used the focus group technique in addition to the committee translation method followed by think-aloud interviews with cognitive probing.

Cognitive interviewing

The second step in the process involved testing the reconciled version of the translated instrument using cognitive interviewing. This approach focuses on the cognitive processes that respondents use to answer survey questions and is useful to identify any potential problems or errors.^[14,15] The cognitive interviewing process involves an interviewer who probes a respondent's comprehension, confidence, recall, and response processes on the basis of the response.^[15]

Cognitive interviewing is used to ensure that the investigators and the respondents share a common understanding about the meaning of the items, and importantly, that they share the intended meaning, as recommended by DeVellis.^[16] This is achieved by identifying confusing words and phrases and testing for problems by mapping responses to the response categories. All issues thus identified are corrected, and then testing is continued until each question is understood clearly and accurately, thus contributing to the validity and reliability of the translated instrument. The key point of this process is that it can often reveal problems that would otherwise be overlooked.^[16]

Cultural differences affecting quality of life instrument translation

People's construction of a sense of subjective well-being depends on the culturally-based knowledge, traditions, and practices to which they have been exposed.^[17] East Asians and Westerners can display culturally divergent cognitive processes related to subjective well-being. A series of studies about subjective well-being by Wirtz *et al.*,^[17] suggested that East Asians and Westerners use different cultural theories to construct and reconstruct their life experiences. For example, Westerners appeared to be more motivated to recall positive affect than negative affect, whereas the reverse appeared to be so for East Asians. To translate the QLI from English into Japanese, therefore, it was important to accommodate for differences in cognitive processing between Americans and Japanese in terms of subjective well-being. These differences are influenced by accumulated knowledge about the world, in addition to linguistic information such as word meaning and syntax, when interpreting what a question is trying to say.^[18]

Another difference that could potentially affect the translation was cognitive style. It has been argued that East Asians including Japanese have a holistic cognitive style, whereas Westerners have an analytic cognitive style.^[19] The holistic reasoning is sensitive to background information and context, while analytic reasoning focuses on target information.^[20] Thus, a straightforward literal translation of the QLI into Japanese could result in misinterpretation, if Japanese respondents retrieve information using a different reasoning pattern from Americans. In addition, Japanese culture, similar to Chinese and Korean culture, is characterized as having a "collectivist" as opposed to "individualist" orientation, which may influence cognitive activities.^[21] Thus, when Japanese patients form judgments about their satisfaction or dissatisfaction with life, their collectivist orientation would affect these judgments. It has also been argued that when East Asians describe themselves, their descriptions are more likely to be influenced by context than are Westerners' descriptions.^[22] Self-assessment by the Japanese appears to be based less on "what do *I* think or feel?" and more on "how am *I* viewed by *others*?"^[23]

Methods

The translation committee began work on translating the QLI in February 2014, and the cognitive interviewing commenced in July 2014. All cognitive interviewing and item revision were completed by February 2015.

Translation committee

The committee in this study included two Japanese nursing researchers, one of whom is an expert on the QOL of Japanese cancer patients, two Japanese/English language experts, and an adjudicator who was an original author of the QLI. The committee approach proceeded in the steps outlined in Table 1. The deliberations among committee proceeded in accordance with the Census Bureau Guidelines.^[24]

Cognitive interviews

In our study, we used the cognitive interviewing method known as "think-aloud" interviewing, utilizing an interview guide to aid the interviewing process.^[15,18] In think-aloud interviewing, an interviewer reads each question to a respondent and listens while the respondent "thinks aloud" through the process of arriving at an answer to the question.^[15] The interviewer explores the thinking processes by asking probes, some of which were generated in advance (asked of everyone), and others that were unique for the individual respondent. Our interviewers used an interview guide to help probe the patients' cognitive processes, listing probes to be asked of all respondents, particularly regarding issues that had generated prolonged

discussion among the translation committee. The probing questions were asked to explore all four aspects of cognitive processing: question interpretation, information retrieval, judgment formation, and response.^[15,25] A summary of the cognitive interviewing is shown in Table 2.

The reading level of the original QLI is fourth grade, as assessed by the Flesch-Kincaid Readability Test. The reading level of the translated QLI was also fourth grade. According to the teaching guidelines of the Ministry of Education, Culture, Sports, Science, and Technology of Japan,^[26] students with third- and fourth-grade reading levels in Japan can read text with the ability to catch key points of sentences and the relationships between paragraphs.

Cognitive interview participants

Approval was obtained from the Institutional Review Board of the University Hospital, in which this study was conducted. Participating patients, a convenience sample, were introduced to the study by a physician specializing in pancreatic cancer. Cognitive interviews were conducted with eight ambulatory patients with pancreatic cancer (five men

and three women). Their mean age was 65.9 years (standard deviation [SD], 9.4; range: 53–81); the mean time since diagnosis was 23.3 months (SD, 17.4; range: 2–50); and five of the patients had undergone surgical treatment.

Results

Step 1: Creating the initial translation

During the initial stages of the translation of the QLI into Japanese, some issues arose. Those that required particularly careful deliberation were linguistic issues about the word “life,” cultural issues about religious traditions and beliefs, and practical issues about education and financial needs.

Linguistic issues

In the QLI, the word “life” is used in three satisfaction items (and their paired importance items): “How satisfied are you with the amount of control you have over your life?”; “How satisfied are you with your life in general?”; “How satisfied are you with the amount of worries in your life?” The word “life,” as it is used in the QLI, is intended to mean “daily life” for some items and the “life from birth to death” for others. In English, one word, “life,” covers both these meanings, whereas in Japanese two distinct words are used, *seikatsu* and *jinsei*, to distinguish them from each other. *Seikatsu* refers to life as one’s daily existence and by default refers to one’s current situation. *Jinsei*, on the other hand, refers to human life as one’s existence from conception to death and is a more abstract concept. Therefore, when translating the QLI into Japanese, we had to carefully decide whether *seikatsu* or *jinsei* was truer to the original meaning of the items.

For “control over life,” we chose to use the Japanese word *seikatsu* because the idea of “control over life” as used in the QLI refers to control over the things that happen in one’s daily life, in other words, being able to make decisions about one’s daily life and to carry them out. Some people, in particular, the sick or the elderly, can feel powerless in their lives as if they have no control over the things that happen to them. In contrast, other people feel that they have the power to make decisions that will control or influence the course of their lives. We had difficulty finding a phrase in Japanese that literally encapsulates the concept of control over life as it appears in the QLI, but finally, decided upon the translation *Keikakutekini seikatsu dekiru* that renders the meaning of living intentionally or acting according to one’s own volition.

For the question “Are you satisfied with your life in general?”, we selected the Japanese word *jinsei* as this question is asking for a general evaluation of one’s entire life overall. We considered that the word life coupled with

Table 1: Steps in the committee approach

Steps	Approach
1	The committee members (aside from the adjudicator) individually translated the QLI from English into Japanese
2	The committee met to compare their respective translations, discuss the differences, and decide on the best translations in terms of semantic and conceptual accuracy, cultural appropriateness, and completeness
3	Through multiple consultations with the adjudicator/author of the QLI (in real time and via email), the committee members agreed on a reconciled version of the Japanese QLI via consensus

QLI: Quality of Life Index

Table 2: Summary of the cognitive interviewing

Interviewers/respondents

Two members of the translation committee, who are researchers in nursing science, carried out the cognitive interviews at an university hospital with 8 ambulatory pancreatic cancer patients

Steps	Procedures
1	The interviewers individually recorded each interview via written reports and met to discuss the results and propose potential modifications to the reconciled version of the QLI in Japanese. Thus, changes were made via an iterative process, with new wording tested in subsequent interviews
2	After 6 interviews were completed, one of the interviewers met in person with the adjudicator/author to discuss modifications to ensure the semantic, conceptual, and normative equivalence of the translation. Revisions were made to the reconciled version on the basis of that discussion
3	The revised version was tested with two additional interviews, with no additional problems identified
4	The committee met to give final confirmation of the modified reconciled version of the Japanese QLI, make final decisions about the translation and discuss its suitability for subsequent data collection in future work

QLI: Quality of Life Index

the term, in general, is more closely encapsulated by the broader, universal, and multifaceted nature of the Japanese word *jinsei* than by the more specific word *seikatsu*.

The notion of “the amount of worries in your life,” as expressed in the QLI, refers to the burden of worries, stress, troubles, and concerns that a person has in life. The word life here carries the dual sense of both daily life and one’s existence. In this case, we found neither *seikatsu* nor *jinsei* to be fully adequate translations of the original. However, it is common for Japanese people to vocally confess to having worries, but rarely to express what they are or whence they came. Therefore, we decided to delete the phrase “in your life” entirely in the translation, which created a more culturally natural phrasing, while not losing the intended meaning.

Cultural issues

An issue that generated discussion concerning cultural adaptation was the items focusing on “your faith in God.” Japanese cultural religious traditions are not rooted in a monotheistic understanding of God but tend to be a syncretistic blend of polytheistic Japanese Shintoism and Japanese forms of Buddhism. Therefore, we chose a term meaning piety (*shinkoushin*), a term that is usually used in a religious sense, to shift the focus more to the patient’s own spirituality than to faith in a particular deity. Thus, the satisfaction item essentially asks, “How satisfied are you with your own spirituality?”

Other questions of the QLI that received significant attention involved the phrases “your education” and “your financial needs.” In Japan, a person’s academic background or their individual financial situation is generally private issues, and Japanese people are not used to being asked about them directly. We chose to interpret the word “education” with the Japanese word *kyoiku*, which carries a broad concept of education, in order not limit the scope solely to the academic background. For the translation of “your financial needs,” we chose the Japanese phrase *keizairyoku* meaning economic resources or economic capability. This translation implicitly asks about personal financial needs without having to include the word “your,” thus depersonalizing the question and thereby makes it more palatable to Japanese respondents.

Step 2: Cognitive interviews

During the cognitive interviewing process, most respondents could easily repeat the questions appropriately in their own words, provide an appropriate response, and explain their thinking. For six questions, however, we found that they had difficulty. The translations of these questions were then revised, and the questions were retested with new respondents in subsequent cognitive interviews.

Listed below are the six items that were changed, along with details of the patients’ responses, the revisions made, and the reasoning behind the revisions. The items are listed as they correspond to the difficulty respondents had with question interpretation (three items), information retrieval (two items), or response editing (one item). There were no problems identified with judgment formation; all participants were able to map their responses to the response choices appropriately after the problems with the stem questions were corrected. Examples of problems brought to light by the cognitive interviewing are shown in Table 3.

Discussion

This detailed presentation provides an illustration of errors that could easily be made, using only the traditional forward-backward translation technique with bilingual translators. Both the committee approach and cognitive interviews were needed to identify issues that subsequently would have threatened the reliability and validity of the Japanese version of the QLI. It is important to note that bilingual people, because they can work in two languages, are not able to identify all the issues that will be problematic for monolingual people, as originally pointed out by Warnecke *et al.*^[25] Thus, the cognitive interviews with monolingual Japanese cancer patients added a level of accuracy that could not have been obtained otherwise. Problems were identified and corrected, and wording re-tested, to confirm the target audience interpreted the questions as intended, which is essential for validity. In addition, the reliability of the translated questionnaire was enhanced by correcting wording that could be interpreted in more than one way. In addition, the participation of the author of the QLI, who was intimately familiar with the original intended meaning of the items, was crucial for ensuring the conceptual match between the original and the translation.

Questions about the respondents’ sex lives remained too sensitive for the response, even when phrasing as gently as possible. Japanese respondents found the concept itself to be culturally unacceptable for face-to-face discussion in an interview, particularly a cognitive interview with the discussion. Nevertheless, sexuality is an integral aspect of our humanity and a critical aspect of QOL, and sexuality and sexual activity is often affected by chronic illnesses such as a cancer.^[27] Therefore, the item referring to sex life was retained in the Japanese version of the QLI, as an indispensable component of QOL, particularly in a healthcare context. Further testing will be needed to determine if Japanese respondents will feel more comfortable completing the item by marking responses themselves in privacy, rather than in an interview.

Table 3: Examples of problems found with the cognitive interviewing

Problems with question interpretation		
Original: “How satisfied are you with the amount of energy you have for everyday activities?” (<i>Hibi-no-katsudou wo okonau katsuryoku ni dorekurai manzoku shiteimasuka?</i>)		
Problem	Revision	Consequence
Two patients had different interpretations of our translation of the word energy (<i>katsuryoku</i>), which means one’s capacity for vigorous daily activity. One patient spoke about the importance of vitality and spirituality in her life, while another patient answered that his level of activity was dependent on his physical strength	We replaced the word <i>katsuryoku</i> (energy) with 2 words that are naturally paired in Japanese: <i>tai-ryoku</i> meaning stamina or physical strength and <i>ki-ryoku</i> meaning willpower or vitality, to encompass both the physical and spiritual aspects of energy	With the revision, subsequent patients had a clear understanding of the questions and referred to their energy for everyday activities using the same wording
Original: “How satisfied are you with your education?” (<i>Koremadeni uketa kyouiku ni dorekurai manzoku shiteimasuka?</i>)		
Problem	Revision	Consequence
Before even giving a response to this item, some patients asked what kind of education this question was referring to. One patient asked: “Does this mean education provided to patients from nurses?” And another patient could not see the relevance of the question, commenting: “Education has no relationship to illness.”	The word education as it used in the QLI refers to various kinds of education experienced throughout one’s life including formal and informal education, career education, training, and patient education. Therefore, to clarify this point, we expanded our Japanese translation to ask “How satisfied are you with education of every kind that you’ve received up until the present time.” (<i>Koremadeni uketa samazama na kyouiku ni dorekurai manzoku shiteimasuka?</i>) That way the patients were prompted to consider their various experiences related to the Japanese term <i>kyoiku</i> meaning education	With the revision, subsequent patients were not confused by this question and all correctly interpreted with the intended meaning
Original: “How satisfied are you with your ability to take care of yourself without help?” (<i>Jiritsu-shita seikatsu wo okuru nouryoku ni dorekurai manzoku-shite imasuka?</i>)		
Problem	Revision	Consequence
A patient said that she was unsure as to how to estimate her own autonomy. Another patient asked, “What am I taking care of without help?”	In our original translation of this item, we used the phrase <i>Jiritsu-shita seikatsu wo okuru nouryoku</i> , meaning one’s ability to live an independent daily-life. However, patients could not comprehend what was meant specifically by the notion of independent daily living-whether it meant physical independence or having an independent state of mind. Therefore we reverted to a literal translation of “without help” closer to the original English (<i>tasuke wo karizu ni</i>) so that the emphasis was on independence in daily living rather than on independence of mind	With the revision, subsequent patients who were asked: “Can you repeat this question in your own words?” repeated this question as “living my everyday life without help” and provided a response without difficulty
Problems with information retrieval		
Original: “How satisfied are you with your ability to take care of yourself without help?” (<i>Jiritsu-shita seikatsu wo okuru nouryoku ni dorekurai manzoku-shite imasuka?</i>)		
Problem	Revision	Consequence
Patients had difficulty providing a single answer to this question, explaining, “I would like to have control over my life” and “I am trying to do so.”	For the initial Japanese translation of “control over life,” we used <i>keikakuteki-ni seikatsu-suru</i> , which means living intentionally (acting according to one’s own plan). To revise this item, we added a phrase meaning be able to (<i>dekiru</i>) instead of using the noun capacity in order to convey the “the amount you are able to act according to your own plan.”	With the revision, subsequent patients appropriately recalled aspects of their life over which they were (and were not) able to have control and were able to rate their satisfaction without difficulty
Original: “How satisfied are you with your chances of living as long as you would like?” (<i>Sukinadake ikirareru chansu ni dorekurai manzoku-shite imasuka?</i>)		
Problem	Revision	Consequence
Several respondents said that it is impossible to live as long as they would like. One person said that although everyone would like to live as long as possible, in his case, he was not permitted to think of future things	We replaced the translation of “would like” with the expression <i>nozomu-kagiri</i> that emphasizes hope rather than like to gain a more tempered response from patients. (<i>Nozomu-kagiri ikirareru chansu ni dorekurai manzoku-shite imasuka?</i>)	With the revision, patients were able to answer the question without difficulty; none said it was impossible to live as long as he/she hoped
Problems with response editing		
Original: “How satisfied are you with your sex life?” (<i>Sei-seikatsu ni dorekurai manzoku-shite imasuka?</i>)		
Problem	Revision/consequence	
Most patients did not wish to mark a response because of the embarrassment of broaching this subject in the presence of interviewers. One patient said that it (sex) was not an issue, while another just said that she was old enough not to be troubled by such things	The most sensitive word was used for the Japanese translation of sex, which literally translated into English means (sexual) intimacy, and thus we did not revise this question further. Responses to probes indicated that respondents understood what the question was asking. The reason that most patients chose not to provide a response was judged to be due to cultural characteristics, rather than to translational or comprehension issues. Generally speaking, Japanese are not used to expressing themselves on the topic of their sex lives, due to embarrassment related to cultural mores. It may be that more would have answered if allowed to do so in private, without discussion of their thought process	
QLI: Quality of Life Index		

There was also a strong possibility that some Japanese patients would not answer the question about faith in God-given that only 20% to 25% of Japanese reportedly describe themselves as having a specific religion or religious belief.^[28] Considering this, we decided to translate “faith in God” with a more general term meaning “piety,” and the patients in our cognitive interviewing were able to answer the question without hesitation.

Research limitations

Although we were able to reach the point where no additional changes were required, we had completed cognitive interviews with only eight patients, and all had the same type of cancer. Interviewing additional respondents from different Japanese populations (such as patients with other cancers and in other clinical settings) will be needed to ensure the translation applies equally well across the Japanese population.

Conclusions

Cognitive interviewing was essential for ensuring the QLI’s cultural and functional adaptation into Japanese, to create an appropriate instrument for use with Japanese cancer patients. This process made it possible, as the next step, to administer the translated QLI as a questionnaire survey to establish its reliability and validity. The Japanese QLI holds great promise as a tool for evaluating the impact of cancer and its treatment from the patient’s perspective and thereby contributes to improving the QOL of Japanese cancer patients.

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Conflicts of interest

There are no conflicts of interest.

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