Clinical Research

Validation and adaptation of the Indonesian version of thyroid cancer quality of life questionnaire

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ABSTRACT

BACKGROUND The rising incidence of thyroid cancer in Indonesia has become a public health concern. This study was aimed to evaluate the validity of the thyroid cancer-quality of life-Indonesian version (ThyCa-QoL-ID).

METHODS This cross-sectional study involved translating the original ThyCa-QoL questionnaire from English to Indonesian (T1), which was then back-translated into English (T2). The T2 questionnaire was compared with the original ThyCa-QoL questionnaire to refine T1, resulting in T3. The T3 questionnaire underwent cognitive and transcultural validation through individual assessment and focus group discussions with 10 doctors and 10 nurses at Cipto Mangunkusumo Hospital and St. Carolus Hospital, and 5 patients with thyroid cancer from St. Carolus Hospital. This process ensured cultural, language, and literacy adaptation processes for patients across different age groups.

RESULTS The ThyCa-QoL questionnaire demonstrated validity, with all questions showing correlation calculation (r) above the r table. Test-retest reliability was measured by calculating the intraclass correlation coefficient for each question on the ThyCa-QoL questionnaire. The reliability test can be seen in the value of Cronbach's alpha (0.915), exceeding the standard Cronbach's alpha value standard (0.6).

CONCLUSIONS The ThyCa-QoL-ID was confirmed as a valid and reliable tool for assessing the QoL of patients with thyroid cancer in Indonesia.

KEYWORDS questionnaire, reliability and validity, thyroid cancer

The incidence of thyroid cancer is increasing in Indonesia, presenting a considerable public health challenge.[1] To comprehensively understand the quality of life (QoL) of patients with thyroid cancer, a holistic approach that includes medical, psychological, social, and emotional factors is essential. However, the need for valid and reliable QoL assessment instruments for both clinical and research purposes remains unmet in Indonesia. The thyroid cancer-quality of life (ThyCa-QoL) questionnaire is a well-established tool developed in English to assess QoL in individuals with thyroid cancer. Although it has been widely used internationally, it has not yet been translated or validated in the Indonesian context. ThyCa-QoL is specifically designed to capture issues unique to patients with thyroid cancer that generally QoL questionnaires may not address.[2,3] This study aimed to translate and validate the ThyCa-QoL questionnaire for use in Indonesia, and to provide a

reliable instrument to assess the QoL of patients with thyroid cancer, encompassing medical, psychological, social, and emotional domains, for both clinical and research applications.

METHODS

This cross-sectional study was approved by the Ethics Committee of the Faculty of Medicine, Universitas Indonesia – Cipto Mangunkusumo Hospital (No: KET-145/UN2.F1/ETIK/PPM.00.02/2023). Prior to translating and validating the ThyCa-QoL questionnaire into Indonesian, permission was obtained from the original developer of the English version, Olga Husson, PhD. A certified translator (RSH), who has held this certification since 2004, translated the original questionnaire (T1) into Indonesian. Another certified translator (DJ), who has been a translator since 2011 and an interpreter since 2013, conducted the back-translation into English (T2). The comparison of each version can be seen in Supplementary Table 1. Revisions to the T1 questionnaire were based on a comparison between T2 and the original questionnaire to ensure the suitability, accuracy, and adaptability of the translation to the Indonesian cultural context. The revised version was referred to as the "T3 questionnaire."

The aim of cross-cultural and linguistic validation, which is essential for translating a qualitative psychometric questionnaire and involves individual assessments and group discussions, is to ensure accessible language for medical personnel (e.g., doctors and nurses) and the public (e.g., patients, families, and caregivers). Each participant was provided with a questionnaire for individual assessment, brainstorming, and correction or editing of each item according to their understanding. Subsequently, the authors guided a group discussion, brainstorming each question until all participants understood the intended meaning of the item. The T3 questionnaire was administered at St. Carolus Hospital to 10 doctors, 10 nurses, and 5 patients with thyroid cancer. The doctors included internal medicine doctors with an endocrinology subspecialty, general practitioners with an internal medicine specialty, and general practitioners. The nurses were employed at the Endocrine Metabolic Polyclinic of Cipto Mangunkusumo Hospital and the Internal Medicine Clinic of St. Carolus Hospital. This process was performed to assess cultural, language, and literacy adaptation, including cognitive and transcultural validation across different age groups. Feedback from the participants was used to refine the final edits before validation testing was conducted. Several modifications were made, including linguistic edits such as grammatical corrections and vocabulary adjustments to improve clarity; removal of question 24 regarding patients' sexual life due to cultural sensitivity and its limited relevance to thyroid cancer treatment; and the addition of patient instructions using a five-point scale (0 – not felt at all, 1 – felt a little [sometimes], 2 – felt, 3 – felt quite often, and 4 – always felt) to support accurate responses. Using consecutive sampling, a minimum of 50 participants were selected to meet the requirements for validity and reliability testing. The revised questionnaire (T4) was administered to 50 patients with thyroid cancer at the Endocrine Metabolic Polyclinic of Cipto Mangunkusumo Hospital.

The inclusion criteria were patients with thyroid cancer at any disease stage and post-surgical patients undergoing follow-up or maintenance therapy who were >18 years old, able to communicate and provide the necessary study data, and willing to participate in the interview process. The exclusion criteria were cognitive impairment (e.g., intellectual disability or dementia), inability to speak Indonesian fluently, and illiteracy. Each patient was instructed to complete the questionnaire independently; the authors or research assistants were present to address any questions or concerns from the participants. The data were analyzed for validity and reliability by assessing the correlation coefficient (r) against the r table and conducting internal consistency and test-retest reliability evaluations.

RESULTS

After completing the translation and transcultural, cultural, and literacy validation (T4) of the Indonesian version of the ThyCa-QoL questionnaire, a validity and reliability test was conducted on 50 patients with thyroid cancer at Cipto Mangunkusumo Hospital. The validity test results for each of the 23 questionnaire items are presented in Table 1.

A validity test was performed by comparing the calculated correlation coefficient (r) with the r table value at $\alpha = 5\%$ ($p = 0.05$). Question items in the questionnaire were considered valid if r count > r table and invalid if r count < r table. For a sample size of 50 ($n = 50$), the r table value was 0.2787 ([N−2,α] = [48; 0.05]

Table 1. Comparison of calculated r and r table to assess the validity of each question

Question	r	Summary
Q1	0.606	Valid
Q2	0.541	Valid
Q3	0.464	Valid
Q4	0.532	Valid
Q5	0.527	Valid
Q6	0.588	Valid
Q7	0.563	Valid
Q8	0.583	Valid
Q9	0.540	Valid
Q10	0.739	Valid
Q11	0.519	Valid
Q12	0.505	Valid
Q13	0.611	Valid
Q14	0.515	Valid
Q15	0.541	Valid
Q16	0.482	Valid
Q17	0.619	Valid
Q18	0.520	Valid
Q19	0.495	Valid
Q20	0.781	Valid
Q21	0.810	Valid
Q22	0.738	Valid
Q23	0.732	Valid

= 0.2787). Table 2 lists the output of the r calculation for each question item compared with the r table. For all 23 items, the r value was greater than the r table value (0.2787), confirming strong validity.

A reliability test was conducted using internal consistency and test-retest reliability. Internal consistency was evaluated using Cronbach's alpha, ensuring all items had a corrected item-total correlation above the minimum threshold of 0.4 to be considered valid, indicating strong item discrimination, good inter-item correlations, and an excellent overall score. Test-retest reliability was assessed using the intraclass correlation coefficient (ICC) for each item. The Indonesian version of the ThyCa-QoL questionnaire demonstrated good reliability, with most Cronbach's alpha values considered acceptable (Cronbach's alpha >0.7) and ICC values falling within the moderate (0.5–0.75) or good (>0.75) ranges.

The analysis also showed good results for corrected item-total correlation, Cronbach's alpha values (Table 2), and ICC. The test-retest reliability was measured by calculating the ICC for each question in the ThyCa-QoL questionnaire. The overall reliability test showed a Cronbach's alpha value of 0.915, exceeding the standard threshold of 0.6 and indicating excellent internal consistency. The ICC results showed a reliability coefficient of 0.319 for individual measurements and 0.915 for average measurements, with the latter categorized as very good. The F-test value was statistically significant (p<0.001), indicating consistency across measurements and significant reliability.

Table 2. Reliability of the Indonesian ThyCa-QoL questionnaire: corrected item-total correlation and Cronbach's alpha

Question	Corrected item-total correlation	Cronbach's alpha if item deleted
Q1	0.555	0.911
Q2	0.479	0.913
Q3	0.408	0.914
Q4	0.487	0.913
Q5	0.476	0.913
Q6	0.548	0.912
Q7	0.510	0.912
Q8	0.536	0.912
Q9	0.489	0.913
Q10	0.703	0.908
Q11	0.454	0.914
Q12	0.448	0.913
Q13	0.556	0.911
Q14	0.456	0.913
Q15	0.486	0.913
Q16	0.425	0.914
Q17	0.568	0.911
Q18	0.461	0.913
Q19	0.442	0.913
Q20	0.747	0.907
Q21	0.779	0.906
Q22	0.697	0.908
Q23	0.694	0.908

ThyCa-QoL=thyroid cancer-quality of life

DISCUSSION

Validating the ThyCa-QoL questionnaire in Indonesia is a crucial first step before conducting further research. This process ensures that the translated questionnaire can elicit meaningful feedback

and insights from participants, thereby improving the quality of interactions between patients and healthcare professionals. These insights can subsequently enhance the accuracy and reliability of questionnaire completion.[4,5]

The refined ThyCa-QoL questionnaire was validated in a cohort of 50 patients. Validity and reliability analyses confirmed that all 23 items were both valid and reliable. The validated questionnaire was officially named the thyroid cancer-quality of life–Indonesian version (ThyCa-QoL-ID), and the complete questionnaire can be found in Supplementary Table 3.

Previous studies have investigated the symptoms and challenges affecting the QoL of thyroid cancer survivors, revealing the limitations of existing assessment tools. Hu et al[6] developed and validated the M.D. Anderson Symptom Inventory-Thyroid Cancer module (MDASI-THY) using in-depth interviews and focus groups. This tool identified fatigue, drowsiness, sleep disturbances, stress, and memory issues as the most common QoL-impairing symptoms among thyroid cancer patients. Despite its strong validity and reliability, the MDASI-THY remains underutilized due to limited longitudinal validation and a lack of awareness and adoption among clinicians and researchers.

Similarly, Kim et al[7] employed the QoL-Thyroid and Functional Assessment of Cancer Therapy-General instruments to evaluate QoL in thyroid cancer patients undergoing thyroid hormone withdrawal. However, these instruments are not specific to thyroid cancer, which limits their relevance. General QoL instruments such as the short form survey 36, Nottingham Health Profile, Profile of Mood States, and visual analog scale have also been used in this context. However, these tools often fail to capture thyroid cancer-specific complaints, especially those following surgery or treatment—such as symptoms related to radiofrequency ablation or thyroid-stimulating hormone suppression therapy with levothyroxine. This underscores the need for QoL tools that are tailored to the unique experiences of patients with thyroid cancer.[8]

Thyroid-specific QoL questionnaires must fill the gaps in assessing the unique challenges encountered by this patient population. Although the Thyroid Patient-Reported Outcome Questionnaire addresses a range of thyroid conditions, its emphasis on benign thyroid disorders limits its applicability to thyroid cancer. To bridge this gap, several thyroid cancer-specific QoL instruments have been developed since 1997, including the MDASI-THY, QoL-Thyroid, Thyroid Cancer Assessment Tool, ThyCa-QoL, Thyroid Cancer Health-Related Quality of Life, and the EORTC Thyroid Cancer-Specific QoL Questionnaire (Thy34).[9] Among these, the ThyCa-QoL questionnaire has gained widespread recognition for its brevity, specificity, comprehensiveness, and user-friendliness in assessing QoL in thyroid cancer patients. ThyCa-QoL has also been translated and validated in multiple languages, enhancing its global utility.[10–13] ThyCa-QoL was developed using rigorous, evidence-based methodologies, ensuring its validity, reliability, and broad applicability, especially when compared to other tools such as the MDASI-THY and thyroid cancer adaptive test, which may lack scope or adaptability.[2] Since its development, ThyCa-QoL has become one of the most widely used instruments for evaluating QoL in thyroid cancer patients, reflecting its importance in clinical practice and research.[14]

This study has certain limitations, including the sample size and study setting. Although data were collected from a national referral hospital and a private hospital with a high volume of thyroid cancer cases, future multicenter studies involving several government and private hospitals would improve the representativeness of the sample and enhance the external validity of the findings. In conclusion, the Indonesian translation and validation of the ThyCa-QoL questionnaire followed a systematic and rigorous process to ensure its cultural and linguistic appropriateness for Indonesian patients. The final ThyCa-QoL-ID was successfully adapted for local use through forward-backward translation, cross-cultural adaptation, and qualitative validation involving both healthcare professionals and patients. This version was found to be valid and reliable, providing an effective tool for assessing QoL among Indonesian patients with thyroid cancer. The methodology and findings of this study contribute meaningfully to the literature on patient-reported outcome measure validation and support improvements in healthcare research and practice in Indonesia.

Conflict of Interest

Laurentius Aswin Pramono is the editorial board member but was not involved in the review or decision-making process of the article.

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