

## Quality of Life in Thalassemia Major Patients: Reliability and Validity of Indonesian Version of TranQol Questionnaire

Billy Ng Setiawan Rachmat Poengoet, Ellyana Sungkar, Tri Damiati Pandji

Department of Physical Medicine and Rehabilitation, Faculty of Medicine, Universitas Padjadjaran-Dr. Hasan Sadikin General Hospital, Bandung

### Abstract

**Objective:** To determine the validity and reliability of TranQol questionnaire that has been translated into Indonesian to be used in Indonesian thalassemia major patients. The quality of life problems among these patients can be detected earlier because TranQol is more precise compared to the Pediatric Quality of Life Inventory (PedsQLTM), World Health Organization Quality of Life Instruments (WHOQOL), and SF-36 Questionnaire.

**Methods:** This study was conducted in Bandung, Indonesia from October 2015 to March 2016 and used a standard "forward-backward" translation procedure. It involved 60 adults and 73 children who are thalassemia major patients, and 71 parents of patients in Dr. Hasan Sadikin General Hospital. TranQol was processed through forward and backward translation approach and evaluation was conducted by the TranQol author. After the translation process, a cognitive debriefing was performed and the translated TranQol was tested to all subjects.

**Results:** Cronbach's alpha  $>0.7$  was used for all TranQol categories. Front validity and content validity testing was performed. The internal validity results showed that some questions were not valid.

**Conclusions:** TranQol reliability in Indonesian language for every category is good. Validity for TranQol in Indonesian language shows that the translated TranQol is not quite suitable that it still cannot be used.

**Keywords:** TranQol Indonesia, validity Indonesia, reliability Indonesia

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### Introduction

Thalassemia is a monogenic disease that is caused by the disturbance in the hemoglobin formation that is observed around the world.<sup>1</sup> India has alpha thalassemia cases of 12.9% and beta thalassemia cases of 3-4%.<sup>2,3</sup> Beta thalassemia is mostly found in Mediterranean countries, Middle East, Middle Asia, India, South China and countries along North Africa and South America beach.<sup>4</sup>

The Indonesian Thalassemia Foundation-Association of Thalassemia Patients' Parents or known as YTI-POPTI (*Yayasan Thalassemia*

*Indonesia-Perhimpunan Orang Tua Pasien Thalassemia*) has reported increased number of thalassemia patients in Indonesia to 7,028 in 2015.<sup>5</sup> The prevention of thalassemia is difficult because of its genetic nature.

Blood transfusion and iron chelating agent increase the survival rate of thalassemia major patients. They will have more opportunities to reach higher education, to work, and to have a better quality of life. In addition, patients may experience complications from the procedure (i.e: osteoporosis, infertility and psychiatric problem). Iron absorption problem in guts and blood transfusion can lead to chronic health problems due to iron accumulation in the body. These will affect thalassemia patients' quality of life.

Research has been done in many countries to evaluate thalassemia patients' quality of life.

### Correspondence:

Billy Ng Setiawan Rachmat Poengoet, Department of Physical Medicine and Rehabilitation, Faculty of Medicine, Universitas Padjadjaran-Dr. Hasan Sadikin General Hospital  
Jl. Pasteur No. 38, Bandung, Indonesia  
e-mail: billyscorp@yahoo.com

Some questionnaires are already used to assess it, such as Pediatric Quality of Life Inventory (PedsQL™), the World Health Organization's Quality of Life Instruments (WHOQOL), and SF-36 Questionnaire.<sup>6-11</sup> These are not specific enough for thalassemia patients.

TranQol was created and published on July 22, 2013. TranQol is a self-report tool used in children, adult, parents or proxy.<sup>12,13</sup> There are 4 groups of questions in this tool: physical health, emotional health, family, school and career. There is only one question regarding the sexual aspect in this tool. The original TranQol have been evaluated for its reliability and validity. It is already acknowledged as a valid and reliable tool to be used specifically for thalassemia patients.

Original English TranQol cannot be used in Indonesia because the different interpretation will reduce its validity and reliability. Hence, its has to be translated and evaluated for its validity and reliability before it can be used in Indonesia.

**Methods**

A standard forward and backward translation procedure was performed by native speakers for the source and target languages after approval was gained from the author and Mapi Research Institute. The procedure was based on Linguistic Validation of a Patient Reported Outcome Measure guideline. After that, a cognitive debriefing was conducted. The result was consulted to the author. The final TranQol in Indonesian language was then distributed for a try out among thalassemia patients. This involved 60 adult and 73 child thalassemia major patients and 71 parents, as proxy, who were selected randomly. The study has received ethical approval from the Ethics Committee of Dr. Hasan Sadikin General Hospital, Bandung and Health Research Ethics Committee Faculty of Medicine Universitas Padjadjaran.

The statistical analyses were performed using a computerized program. Cronbach's alpha was used to assess the reliability and the internal consistency of the questionnaire. Validity was evaluated using the Spearman correlation.

**Results**

The mean age of the respondents in this study was 12.60 for children, 23.34 for adults, and 39.87 for parents and proxy. Blood

transfusion frequency (in weeks) for children was 3.73 and 4.95 for adults. The reliability of TranQol in Indonesian language was tested by Cronbach's alpha. The reliability was proven good with >0.7 Cronbach's alpha for children, adults, parents, and proxy (i.e. 0.806 for child, 0.877 for adult, 0.926 for parent, and 0.755 for proxy).

Validity was tested by correlating each with the total score. TranQol in Indonesian validity testing included all 38 questions for parents but not included 9 of 28 questions in children, 10 of 36 questions for adults, 12 of 28 questions for proxy because those questions were left blank. This interfered the correlation with total score. Those unanswered questions could be not included in the evaluation based on the result of a discussion with the author of TranQol (Table 3 and 4).

**Discussion**

The questions in the TranQol are more targeted for thalassemia patients when compared to Pediatric Quality of Life Inventory (PedsQL™), the World Health Organization Quality of Life Instruments (WHOQOL), and also the SF-36 Questionnaire. Some questions in the TranQol ask about the direct impact of thalassemia to the patients's life. The impact of regular transfusion and iron removal treatment that are specific for thalassemia were asked too. The benefit is that thalassemia patients's quality of life problems can be detected earlier, making early intervention possibler for optimal result.

TranQol in Indonesian language for children did not include all questions. Questions 3, 6, 7, 8, 12, 13, 18, 22 and 23 are excluded. Question number 3 is about pain, 6 is about social activity, 7 is about painful examination, 18 is about negative effects of thalassemia, 22 and 23 are about decision of thalassemia care which were considered not specific and hard to be understood by children.

**Table 1 Subject Characteristics**

	Children	Adult	Parent or Proxy
N	73	60	71
Mean	12.60	23.34	39.87
Median	13	22	39
Minimum	7	19	23
Maximum	17	39	62

**Table 2 Internal Validation for Children and Proxy**

Children	Spearman (R)	p Value	Proxy	Spearman (R)	p Value
Question 1 and score	0.228	0.052	Question 1 and score	0.5919	0.0000
Question 2 and score	0.531	0.000	Question 2 and score	0.5550	0.0000
Question 4 and score	0.431	0.000	Question 4 and score	0.6481	0.0000
Question 5 and score	0.563	0.000	Question 5 and score	0.7570	0.0000
Question 9 and score	0.442	0.000	Question 7 and score	0.5764	0.0000
Question 10 and score	0.604	0.000	Question 8 and score	0.6085	0.0000
Question 11 and score	0.593	0.000	Question 9 and score	0.6007	0.0000
Question 14 and score	0.594	0.000	Question 10 and score	0.6619	0.0000
Question 15 and score	0.332	0.004	Question 11 and score	0.5892	0.0000
Question 16 and score	-0.017	0.885	Question 12 and score	0.6237	0.0000
Question 17 and score	0.266	0.023	Question 13 and score	0.7498	0.0000
Question 19 and score	0.122	0.304	Question 14 and score	0.7178	0.0000
Question 20 and score	0.519	0.000	Question 15 and score	0.4486	0.0001
Question 21 and score	0.379	0.001	Question 18 and score	0.4660	0.0000
Question 24 and score	0.515	0.000	Question 22 and score	0.3997	0.0006
Question 25 and score	0.743	0.000	Question 23 and score	0.2985	0.0121
Question 26 and score	0.669	0.000			
Question 27 and score	0.578	0.000			
Question 28 and score	0.509	0.000			

Question number 8 about feeling different from others, 12 about feeling angry, 13 about feeling sad are subjective and cannot be well understood by children under 10 years of age.

TranQol in Indonesian language for adults did not include questions 10, 15, 24, 25, 31, 32, 33, 34, 35, and 36. Question number 10 about thalassemia impact in preventing activity, 15 about feeling anxious, 24 about feeling different with others were viewed to be not specific enough to be understood that it was decided not to include them in the Indonesian version of TranQol. Question 25 about sexual aspect was not answered by many participants because many respondents were not married yet or they consider the question is too sensitive from the perspective of Indonesian culture, which considers discussion on sexual topic as taboo. Questions number 31, 32, 33 on school and 34, 35, 36 on work were not answered by many respondents because most of them did not continue their education to the higher education level or work due to their disability.

TranQol in Indonesian language for proxy did not include questions 3, 6, 16, 17, 19, 20, 21, 24, 25, 26, 27, and 28. Question number 3 on pain felt by patient, 6 on social activity, 16 family support, and 17 on friends support were considered to be not specific so they would be hard to answer. Questions number 19, 20, 21 on relation between patient and his/her family were not answered because proxy did not have exact knowledge, patient had lost his/her parents, or patient was not carried by his/her parent anymore. Parents were also considered proxy that it may lead to confusion. Question number 24 regarding the child opinion about family economic problem was not answered by many because they did not know the answer or the children were too young to have opinion about it. Question number 25, 26, 27, 28 about school are not relevant for those who do not get higher education.

All questions in the Indonesian version of TranQol for parents were well understood and answered well by all the respondents. Spearman correlation analysis was done

**Table 3 Internal Validity for Adults and Parents**

Adult	Spearman (R)	p Value	Parent	Spearman (R)	p Value
Question 1 and score	0.168	0.203	Question 1 and score	0.2599	0.0286
Question 2 and score	0.056	0.670	Question 2 and score	0.4118	0.0004
Question 3 and score	0.486	0.000	Question 3 and score	0.3286	0.0051
Question 4 and score	0.399	0.002	Question 4 and score	0.5990	0.0000
Question 5 and score	0.479	0.000	Question 5 and score	0.5503	0.0000
Question 6 and score	0.115	0.386	Question 6 and score	0.1765	0.1438
Question 7 and score	0.593	0.000	Question 7 and score	0.2694	0.0231
Question 8 and score	0.491	0.000	Question 8 and score	0.5901	0.0000
Question 9 and score	0.394	0.002	Question 9 and score	0.5800	0.0000
Question 11 and score	0.546	0.000	Question 10 and score	0.6397	0.0000
Question 12 and score	0.514	0.000	Question 11 and score	0.6187	0.0000
Question 13 and score	0.541	0.000	Question 12 and score	0.5030	0.0000
Question 14 and score	0.452	0.000	Question 13 and score	0.5341	0.0000
Question 16 and score	0.272	0.037	Question 14 and score	0.4115	0.0004
Question 17 and score	0.049	0.711	Question 15 and score	0.5333	0.0000
Question 18 and score	0.681	0.000	Question 16 and score	0.5017	0.0000
Question 19 and score	0.719	0.000	Question 17 and score	0.5155	0.0000
Question 20 and score	0.500	0.000	Question 18 and score	0.4975	0.0000
Question 21 and score	0.669	0.000	Question 19 and score	0.7320	0.0000
Question 22 and score	0.693	0.000	Question 20 and score	0.5324	0.0000
Question 23 and score	0.203	0.120	Question 21 and score	0.5931	0.0000
Question 26 and score	0.181	0.166	Question 22 and score	0.4294	0.0002
Question 27 and score	0.522	0.000	Question 23 and score	0.6494	0.0000
Question 28 and score	0.438	0.000	Question 24 and score	0.5892	0.0000
Question 29 and score	0.453	0.000	Question 25 and score	0.2858	0.0165
Question 30 and score	0.577	0.000	Question 26 and score	0.3312	0.0281
			Question 27 and score	0.5150	0.0000
			Question 28 and score	0.5376	0.0000
			Question 29 and score	0.6093	0.0000
			Question 30 and score	0.6099	0.0000
			Question 31 and score	0.5402	0.0000
			Question 32 and score	0.2301	0.0572
			Question 33 and score	0.1870	0.1212
			Question 34 and score	0.6671	0.0000
			Question 35 and score	0.5765	0.0000
			Question 36 and score	0.5977	0.0000
			Question 37 and score	0.5089	0.0000
			Question 38 and score	0.6412	0.0000

for every question with the total score after selection of questions. Results of correlation analysis in this study show that 2 questions in TranQol for children are not valid (Table 3). Question number 16 about family support seems to be not specific so that it is difficult to answer. Question number 19 about decision on treatment is too hard to be understood by children and they usually follow their parents' decision. Question number 6 in TranQol for adult is not valid. Question number 1 on sleep difficulty, 2 on pain, 6 on ability to do activity, 17 on telling thalassaemia to others, 23 on guilty feeling when do not follow the treatment will be better understood if they are simplified and made more specific. Question number 6 on

feeling disturbed by their child treatment and number 33 on support from friends might be difficult to understand due to their unspesific nature. All selected TranQol questions for proxy are valid.

In conclusion, the reliability of Indonesian version TranQol is good but many questions from each category are still not valid. Further studies are needed to validate the translated TranQol before it can be used in Indonesia. It can be considered to translate TranQol by a certified translator. TranQol for proxy has the highest number of unanswered questions. Decreased concentration and motivation may be caused by the fact that parents had to answer TranQol for proxy in succession.

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