

Development and Reliability of the THAICLEFT Quality of Life Questionnaire for Children with Cleft Lip/Palate and Families

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Objective: The objective of this study was to develop and test the reliability of the THAICLEFT Quality of Life (QoL) questionnaire for families of children coping with the problems associated with cleft lip/palate (CLP).

Material and Method: After reviewing the literature on QoL measurements, the THAICLEFT QoL questionnaire was developed. The 27 families registered with the Tawanchai CLP service registry completed the questionnaire.

Results: The Cronbach's alpha, i.e., the internal consistency and reliability, of 24 Quality of Life questionnaires was calculated. Values > 0.7 are considered acceptable and the value of the THAICLEFT QoL questionnaire was 0.861.

Conclusion: Using the THAICLEFT QoL questionnaire can help the healthcare provider to support parents and understand whether they are able to care for the patients and their psycho-economic needs.

Keywords: Quality of life, Psycho-economic needs, Cleft lip, Cleft palate, CLP

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Non-syndromic orofacial clefts in children have a prevalence of 2.5 per 1,000 in Thailand; thus, there are currently ~100,000 children with a facial cleft. Treatment requires a multidisciplinary approach including: plastic surgery, maxillofacial dentistry, orthodontics, speech therapy, nursing and psychosocial healthcare.

The measurement of performance should be related to the clinical outcomes, the process of care and total quality of life of patients and families. Total quality management is based on three simple rules: (1) work to the patient's satisfaction; (2) performance of the therapists; and, (3) continuous improvement by finding, learning and implementing new techniques⁽¹⁾. Quality of life (QoL), according to the WHO definition, is the individual's perception of their position in life within the context of the culture and

value system in which they live and in relation to their goals, expectations, standards and concerns⁽²⁾. Life satisfaction is also related to self-esteem and self-image and their social role⁽³⁾. QoL for the patient also depends on their health or the outcome of treatment. Many studies on QoL in children with orofacial cleft show that they may have disadvantages related to altered speech and/or facial appearance and/or family functioning^(4,5).

'Tawanchai' is Thai for sunshine and the Tawanchai Project of the Faculty of Medicine, Khon Kaen University, brings light and life to children suffering from CLP. The Center for Care and Research of Persons with Cleft Lip and Palate developed a questionnaire to measure the QoL of children with CLP appropriate for the Thai context. The questionnaire can measure total quality management including life satisfaction, family functioning, the clinical outcomes of plastic surgery and dental work, facial appearance, and speech therapy.

Objective

To develop the QoL questionnaire for Families

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of Children with Orofacial Cleft(s) being served by the Tawanchai Cleft Center, Khon Kaen, Thailand, and to test the questionnaire to measure its internal consistency and reliability.

Material and Method

The study was one of the main projects of the Tawanchai Research Center and was approved by the Ethics Committee of Khon Kaen University. We reviewed the quality of life measures used in international studies and research on QoL with regard to cleft lip and palate, orofacial cleft and health-related quality of life from several cleft research centers (*e.g.*, Euro cleft, Canadian QoL of life for children with Developmental disabilities).

The KINDL⁽⁶⁾ questionnaire, a self-reporting type of questionnaire, is commonly used for QoL measurement in children with illness. There are six dimensions each with four items each for QoL: namely, physical well-being, psychological well-being, self-esteem, family, friends, and every-day activities.

The WHOQOL-BREV⁽⁷⁾ was developed by the WHO for the measurement of generic QoL. It is also a self-reporting, self-perception style with four items: physiological, psychological, social relationships and environment. The WHOQOL-BREV have been translate to Thai and validated in the Thai context. The impact on family scale (IOFS) has five items: financial impact, social relationships, personal impact, coping strategies, and concern for siblings.

Based on the foregoing two instruments and notes from the annual meeting in 2009⁽⁸⁾, we developed the THAICLEFT QoL for identifying the needs of children and their families. There are four items covering needs: nursing care, service, economics, satisfaction of clinical outcomes and self-esteem. Altogether the QoL has 24 questions. Each item is rated using a 5-point Likert-type scale (1 = least agree; 5 = strongly agree).

The parents of 27 children with cleft lip and palate answered the questionnaire. The Cronbach's alpha was calculated to test internal consistency reliability.

Results

The THAICLEFT QoL for children with clefts lip and palate and their families was developed. Part 1 is for General Demographic data, Part 2 is Thai GHQ-12 for screening general mental health of the parent and Part 3 is the QoL. There are 24 questions using a 5-point Likert-type scale (1 = least agree; 5 = strongly

agree).

In Part 3, there are five groups of questions: eight on the care of babies and children, three on service needs, four on economic needs, five on satisfaction vis-à-vis outcomes for children, and five on stress and strengths in family relationships. The Cronbach's alpha was calculated. Considering that a value of 0.7 or more is acceptable, our result of 0.861 is very good⁽⁹⁾.

Discussion

A multidisciplinary team is needed to perform many management modalities for patients with orofacial cleft; including, plastic surgeons, dentists, speech therapists, nurses, psychiatrists and psychologists. The team needs to understand all of the needs of the patient and the related family, including the reality that treatment is itself a sort of burden because of the long process. We, therefore, developed a quality of life (QoL) questionnaire, appropriate to Thai context but also maintaining certain universal standards to ensure comparability with other international QoL inventories as sanctioned by the WHO.

The THAICLEFT QoL has 24 questions including needs for the care of babies and children, service needs, economic needs, satisfaction with the treatment outcomes for the affected children, family needs, parent perceptions and psychological stressors. The limitation of our study is the same sort of limitation common to any questionnaire and that is the need for a direct, in-depth interview of the family as a confirmation follow-up.

The Cronbach's alpha determines the internal consistency or average correlation of items. The Cronbach's alpha for the THAICLEFT QoL was 0.86, which indicates a high level of reliability. We, therefore, plan to use the THAICLEFT QoL to assess the QoL of our registered families in further research at the center and for use as a Thai national assessment tool.

Conclusion

The authors hope the THAICLEFT QoL can be used to measure the psycho-economic needs of the families of children with cleft lip/palate in Thailand, and also be useful for further research in the management of cleft lip/palate patients. The reliability of the questionnaire is 0.86 which is very good.

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การพัฒนาและวัดความเชื่อถือของแบบวัดคุณภาพชีวิตประจำวันสำหรับผู้ป่วยภาวะปากแหว่งเพดานโหว่

นิรมล พัจนสุนทร, สุธีรา ประดับวงษ์, ศิริพร มงคลถาวรชัย, ธาโรนี เพชรรัตน์, บวรศิลป์ เชาวน์ชื่น

วัตถุประสงค์: การศึกษานี้มีวัตถุประสงค์ เพื่อพัฒนาและประเมินความเชื่อถือแบบวัดคุณภาพชีวิต "THAICLEFT" ใน เด็กที่มีภาวะปากแหว่งเพดานโหว่ และความต้องการของครอบครัว

วัสดุและวิธีการ: หลังจากทบทวนวรรณกรรม เกี่ยวกับคุณภาพชีวิตแล้วได้พัฒนาแบบสอบถามแล้ว ได้นำไปสอบถามผู้ปกครอง จำนวน 27 ราย ที่ลงทะเบียนในศูนย์ตะวันฉาย

ผลการศึกษา: การทดสอบความน่าเชื่อถือของแบบสอบถาม จำนวน 24 ข้อ โดยวิธี Cronbach's alpha มีค่า $\alpha = 0.861$ ซึ่งมีค่าความน่าเชื่อถือที่ยอมรับได้

สรุป: การพัฒนาและวัดความเชื่อถือของแบบวัดคุณภาพชีวิต THAICLEFT สำหรับผู้ป่วยภาวะปากแหว่งเพดานโหว่สามารถนำมาใช้วัดความต้องการและคุณภาพชีวิต เพื่อนำไปใช้เป็นแนวทางในการให้ความช่วยเหลือผู้ป่วยได้เหมาะสมยิ่งขึ้น