COMPARISON OF TWO HEALTH RELATED QUALITY OF LIFE QUESTIONAIRES IN MALAY CHILDREN WITH STRABISMUS AND THEIR PARENT PROXY

BY

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DISCLAIMER

I hereby certify that the work in this dissertation is my own except for the quotations and summaries which have been duly acknowledged.

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Tan Jin Poi

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ABSTRAK

Pengenalan: Juling merupakan satu penyakit mata yang boleh menyebabkan masalah-masalah kosmetik, fungsi dan psikososial. Penilaian Kualiti Kehidupan Berkaitan dengan Kesihatan (HRQoL) semakin diiktirafkan sebagai satu faktor penting dalam rawatan juling dan merupakan satu instrumen yang penting dalam bidang penyelidikan klinikal. Tetapi, tidak banyak alat penilaian HRQoL juling yang khusus, terutamanya untuk kanak-kanak dan dalam pengetahuan kami, tidak ada penerjemahan Bahasa Malaysia untuk soal selidik juling juga. Dalam kajian kami, IXTQ dan AS-20 versi Inggeris telah diterjemahkan kepada Bahasa Malaysia dan mencapai pengesahan linguistik. Kami harap dua-dua borang soal selidik ini dapat diperkenalkan ke dalam amalan klinikal kami. Selain itu, kajian ini juga membandingkan borang soal selidik IXTQ dan AS-20 versi Melayu yang baru di kalangan kanak-kanak Melayu dengan juling dan proksi ibu bapa mereka.

Objektif: Untuk membandingkan dua jenis borang soal selidik kualiti kehidupan (HRQoL) dalam aspek fungsi dan psikososial di kalangan kanak-kanak Melayu dengan juling dan proksi ibu bapa mereka.

Metodologi: Soal selidik telah diterjemahkan dari Inggeris ke Bahasa Malaysia sebelum diberikan kepada 30 kanak-kanak Melayu dengan juling dan ibu bapa mereka untuk menentukan kebolehpercayaan konsistensi dalaman. Ujian alfa Cronbach telah digunakan. Ini diikuti oleh kajian keratan rentas komparatif yang telah dijalankan di

Klinik dan Wad Oftalmologi, Hospital Universiti Sains Malaysia dari Jun 2012 hingga Jun 2014. Seramai 57 kanak-kanak Melayu berusia 5 hingga 17 tahun dan ibu bapa telah dikumpulkan untuk kajian ini. Kanak-kanak dan ibu bapa kemudiannya diminta untuk mengisi borang soal selidik IXTQ dan AS-20 versi Melayu. Kanak-kanak dan ibu bapa diberikan arahan lisan dan bertulis yang mudah oleh personel terlatih dan diminta untuk menjawab berasaskan pengalaman mereka bulan sebelumnya. Soal selidik terdiri daripada jawapan skala 5 titik jenis Likert. Jumlah purata skor, purata skor sub-skala fungsi dan psikososial telah dikira dan dibandingkan di antara dua-dua soal selidik.

Keputusan: Penilaian konsistensi dalaman untuk semua soal selidik versi Melayu yang baru diterjemahkan kecuali IXTQ Kanak-kanak melebihi nilai alfa 0.90. Nilai alfa untuk AS-20 Kanak-kanak ialah 0.909, 0.912 untuk IXTQ Proksi, 0.948 untuk AS-20 Proksi dan 0.651 untuk IXTQ Kanak-kanak. Terdapat perbezaan yang signifikan dalam jumlah purata skor dan purata skor sub-skala fungsi di antara kedua-dua IXTQ dan AS-20 di kalangan kanak-kanak Melayu dengan juling ($p < 0.001$). Tetapi, didapati tiada perbezaan yang signifikan antara purata skor sub-skala psikososial dua-dua soal selidik dalam kanak-kanak ($p = 0.122$). Semua skor soal selidik IXTQ dan AS-20 Proksi mempunyai perbezaan signifikan ($p < 0.05$). Kajian kami juga mencatatkan skor yang lebih rendah dalam soal selidik IXTQ dibandingkan dengan skor soal selidik AS-20.

Kesimpulan: Jumlah purata skor dan purata skor sub-skala fungsi adalah lebih tinggi dalam soal selidik AS-20 versi Melayu berbanding dengan IXTQ versi Melayu dalam kanak-kanak Melayu dengan juling. Perbezaan ini juga didapati signifikan. Tetapi, perbezaan dalam purata skor sub-skala psikososial di antara dua soal selidik

dalam kanak-kanak didapati tidak signifikan. Untuk ibu atau bapa atau penjaga proksi kanak-kanak Melayu dengan juling, didapati semua purata skor adala lebih rendah di soal selidik IXTQ versi Melayu berbanding dengan AS-20 versi Melayu Proksi. Perbezaan ini didapati signifikan.

COMPARISON OF TWO HEALTH RELATED QUALITY OF LIFE QUESTIONAIRES IN MALAY CHILDREN WITH STRABISMUS AND THEIR PARENT PROXY

ABSTRACT

Introduction: Strabismus is an eye condition associated with cosmetic, functional and psychosocial circumstances. Evaluation of Health Related Quality of Life (HRQoL) is increasingly recognized as an important factor in strabismus management and a crucial tool for clinical research. However, there are not many strabismus-specific HRQoL assessment tools, especially for children and to our knowledge, no Malay translation for strabismus specific questionnaires. The English versions of IXTQ and AS-20 questionnaires were translated into Malay language and achieved linguistic validation in our study in a hope to apply the questionnaires into our clinical practice. This study also compared the newly developed Malay version of IXTQ and AS-20 HRQoL questionnaires in Malay children with strabismus and their parent proxy.

Objective: To compare two health related quality of life (HRQoL) questionnaires for functional and psychosocial aspects in Malay children with strabismus and their parent proxy.

Methodology: The questionnaires were translated forward and backward before they were administered to 30 Malay children with strabismus and their parents to determine the internal consistency reliability. The test for Cronbach's alpha was performed. This was then followed by a comparative cross sectional study conducted in Ophthalmology Clinic and Ward, Hospital Universiti Sains Malaysia from June 2012

until June 2014. A total of 57 Malay children aged 5 to 17 years and their parents were recruited for this study. The children and their parents were then asked to complete the translated Malay version of IXTQ and the AS-20 questionnaires. Children and their parents were given simple verbal and written instructions by a trained personnel and asked to base their responses on their experiences over the previous month. Questionnaires consist of 5 point Likert type scale answer. The total mean scores, functional subscale scores and psychosocial scores were calculated and compared between both questionnaires.

Result: The evaluation of the internal consistency for all our newly translated Malay version questionnaires except for Child IXTQ exceeded an alpha of 0.90. The alpha value was 0.909 for Child AS-20, 0.912 for Proxy IXTQ, 0.948 for Proxy AS-20 and 0.651 for Child IXTQ. There was a significant difference noted in the total mean scores and the functional subscale mean scores between both IXTQ and AS-20 questionnaires in the Malay children with strabismus ($p < 0.001$). There was no significant difference between the psychosocial subscale mean scores of the two questionnaires in the children ($p = 0.122$). In the comparison between the Proxy IXTQ and AS-20, there was a significant difference noted in the total mean scores, the functional subscale and the psychosocial subscale mean scores between both questionnaires ($p < 0.05$). All the scores in AS-20 questionnaires are higher when compared to the scores from all IXTQ.

Conclusion: The total mean score and functional subscale mean score were significantly lower in the Malay version of IXTQ compared to the Malay version of AS-20 in the Malay children with strabismus. There was no significant difference in the

psychosocial subscale mean score between the two questionnaires in the children. The total mean score, functional and psychosocial subscale mean score were significantly lower in the Malay version of IXTQ compared to the Malay version of AS-20 questionnaires in the parent of Malay children with strabismus.

Chapter 1
Introduction

1.0 INTRODUCTION

1.1 Strabismus

1.1.1 Prevalence of Strabismus

Strabismus, also known as heterotropia or squint, is defined as misalignment of the eyes. In other words, the eyes do not point in the same direction. It is an eye condition with cosmetic and functional circumstances (Carlton *et al*., 2008). Carlton et al performed a systemic literature review in 2008 on the prevalence and natural history, the screening methods used, effectiveness of treatment options, and health-related quality of life issues relating to amblyopia and strabismus. They also reported that if strabismus is left untreated, it would persist into adulthood.

Few population-based studies have reported the prevalence of strabismus in children to be in the range of 0.01% to 3.3% globally. Some studies from Malaysia reported a strabismus prevalence of 1.4%-2.2% (Teoh and Yow, 1982; *Goh et al.,* 2005), whereas, it was reported to be 0.8% in Singaporean Chinese children (Chia *et al.*, 2010), 1.9%-3% in China (He *et al.*, 2004), 1.28% in Japan (Matsuo and Matsuo, 2007), up to 3.3% in United States (Chew *et al.*, 1994), 2.8% in Australia (Robaei *et al.*, 2006), and 2.3% in United Kingdom (Williams *et al.*, 2008).

Teoh and Yow (1982) conducted the study in Petaling Jaya, Malaysia, involving 650 school children aged 7. Fourteen (2.2%) of them were found to have strabismus, of which 86% were exotropia, 7% alternating esotropia and 7% hypertropia. Another population-based, cross-sectional survey was done by Goh *et al*. (2005) on 4634 children, aged 7 to 15 years, living in a suburban area near Kuala Lumpur city. They

reported strabismus in 1.4% of the children in which mostly (up to 85%) were exotropia.

Chia *et al*. (2010) carried out a door to door survey in the South-Western region of Singapore, recruiting 3009 children aged 6 to 72 months. They observed a lower prevalence of strabismus (0.8%) among young Singaporean Chinese children. Majority of the strabismic children had intermittent exotropia (58%), followed by constant exotropia (25%) and constant esotropia (12%).

In Guangzhou, China, He *et al.* (2004) studied on 5053 children aged 5 to 15 years and reported prevalence of strabismus to be 1.9% to 3.0%. Most of them were exotropia (80% with near and 86% with distant fixation). Matsuo and Matsuo (2007) carried out a large-scale population-based survey in Okayama Prefecture, Japan. Questionnaires were mailed to elementary schools and a total 86531 children, aged 6 to 12 years participated in the surgey. They observed 1.28% of the children were found to have strabismus where 0.69% were exotropia and 0.28% were esotropia.

In the United States, the Baltimore Paediatric Eye Disease Study examined 2546 white and African American children aged 6 through 71 months and revealed that 3.3% of white and 2.1% of African American children had manifest strabismus. (Friedman *et al.*, 2009). Robaei *et al*. (2006) reported a 2.8% prevalence of strabismus in a population-based cross-sectional study in Sydney. 1739 children aged 6 years was recruited and reported that 54% had esotropia and 29% had exotropia. Whereas in the United Kingdom, Williams *et al.* (2008) reported a 2.3% prevalence of strabismus in 7825 seven year-old children. And it was also reported that 73.4% were esotropia, 21.4% were exotropia and 5.2% had a vertical component.

There are four types of strabismus. They are the horizontal strabismus: esotropia and exotropia; and the vertical strabismus: hypertropia and hypotropia. Esotropia is an inward turning of the eyes or also known as "crossed eyes". Exotropia is an outward deviation of the eyes forming a divergent angle of the eyes or also known as "wall eyes". Hypertropia is an upward deviation of the eyes whereas hypotropia is a downward turning of the eyes. Strabismus is equally common in boys and girls and sometimes runs in families.

The prevalence of the type of strabismus varies based on racial and ethnic background. Exotropia occurs more commonly in the Middle East, subequatorial Africa and the Asian populations than in the United States as quoted from Noorden (1996). Jenkins (1992) made the interesting observation that the nearer a country is to the equator the higher the prevalence of exodeviations. Whereas Europeans, Australians and Americans are predominantly diagnosed with esotropia. The basis of this difference may be in part linked with population-based differences in refractive error. Cotter *et al.* (2011) investigated the risk factors associated with esotropia or exotropia in a population-based cross-sectional prevalence study where 9970 children ages 6 to 72 months from California and Maryland participated. They reported that esotropia is commonly associated with hyperopia, whereas exotropia is more associated with myopia. Yu *et al.* (2002) also reported a higher prevalence of exotropia in Hong Kong as the population becomes less hyperopic.

Sometimes, the child cannot use both eyes together but has to fixate with one or the other. The eye that looks straight at a given time is the fixing eye. Visual acuity diminishes with diminished use of an eye, and suppression amblyopia may develop.

Early treatment usually improves vision and appearance. Generally, the most satisfactory results are achieved if the condition is corrected before the age of seven years old. However, if strabismus is left untreated, it may result in loss of binocularity and depth perception.

1.1.2 Functional effects of Strabismus

In strabismus, there is disruption of binocular vision which leads to images forming in non-corresponding points in both retinae. This causes overlapping of different foveal images from the fixating eye and the deviating eye. Noorden published an article in 1985, explaining that in order to minimize the disorganization and confusion, there is an active inhibition within the retino-cortical pathways of visual input which originates from the fovea of the deviating eye (Noorden, 1985). This mechanism prevents diplopia or confusion due to visual adaptation via anomalous retinal correspondence or known as visual suppression. This will result in poor vision in the non-fixating eye causing amblyopia.

Amblyopia is defined as unilateral or less commonly, bilateral reduced best corrected visual acuity (BCVA) in the absence of organic abnormality of the eye (Noorden, 1985). If left untreated or inadequately treated, it can cause permanent loss of vision.

Although amblyopia generally develops in children aged less than seven years, it can still happen at any age prior to visual maturation. But early accurate diagnosis and treatment of amblyopia should be carried out. Birch and Wang (2009) did a review on the normal maturation of stereoacuity, the stereoacuity deficits associated with infantile and accommodative esotropia and strategies for improving stereoacuity outcomes. They concluded early diagnosis and treatment may result in improved vision, leading to a better prognosis for binocular vision development, a more stable alignment for surgery if required and improved long term quality of life.