

Artikel Asli/Original Articles

Profile and Quality of Life of Children with Dual Sensory Impairment or Deafblindness in Visually Impaired Special Centres (Profil dan Kualiti Hidup Kanak-kanak dengan Kecacatan Dwi-deria atau *Deafblindness* di Pusat Khas Kecacatan Penglihatan)

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ABSTRACT

Coping with dual sensory impairment or deafblindness can be a challenging task for an individual and for the caregiver. Currently limited information is available hence the objective of this study is to determine the profile and quality of life for children with dual sensory impairment or deafblindness. It is hoped that with this information, better rehabilitation programs can be designed for children with deafblindness in Malaysia. A purposive sampling method was adopted. Children with dual sensory impairment were invited to participate in the study. Demographic and hearing loss information was extracted from the children's medical records. Face to face interviews with parents were conducted using the SF-36 quality of life questionnaire. Vision assessment comprising visual acuity, refraction, cover test, external ocular examination and children's behaviour observations was conducted. Four children were identified consistent with the based on sample size calculation and who fulfilled the dual sensory impairment criteria out of the 44 children screened. The mean age was 9.3 ± 2.9 years. A majority of the children were of Indian ethnicity. The category of deafblindness seen was congenital deafblindness with rubella as the main cause. All the children were premature babies but had a normal birth weight. The hearing profile showed the majority of them had bilateral profound hearing loss with the mean pure tone average ranging between 50 dBHL and 120 dBHL. The main type of hearing problem was sensorineural and the majority of children owned hearing aids. The visual profile of the deafblindness children revealed either light perception (LP) and categorised as blind or low to moderate myopia. A majority had esotropia. All the children used braille as a visual aids and children with residual vision used closed circuit television (CCTV). Tactile methods were the main means for communication and majority of the children used a white cane. Behaviour and external observation assessments concurred with the hearing and vision impairment manifested. Quality of life in these subjects was lower in 7 out of 8 SF-36 dimensions as compared to normative values. Congenital deafblindness was the main category found among the children in this study and they had profound vision and hearing losses. Tactile methods are the main means of communication for these children. Their quality of life was affected and introducing deafblindness rehabilitation, which includes a combination of hearing and low vision rehabilitation, will be able to assist them in coping with their daily activities.

Keywords: Dual sensory impairment; deafblindness; visual impairment; low vision; hearing impairment; quality of life; rehabilitation

ABSTRAK

Menghadapi gangguan dwi-deria atau 'deafblindness' boleh menjadi amat mencabar untuk individu dan penjaga. Maklumat sedia ada kini adalah sangat terhad, oleh itu objektif kajian ini adalah untuk menentukan profil dan kualiti hidup kanak-kanak yang mengalami gangguan dwi-deria. Adalah diharapkan dengan maklumat ini, program pemulihan yang lebih baik boleh dirangka untuk kanak-kanak ini di Malaysia. Pensampelan bertujuan telah digunakan. Kanak-kanak yang mengalami gangguan dwi-deria telah dijemput mengambil bahagian dalam kajian ini. Maklumat demografi dan kehilangan pendengaran diambil daripada rekod perubatan kanak-kanak. Temubual bersemuka dengan ibu bapa telah dijalankan menggunakan soal selidik kualiti hidup SF-36. Penilaian visual yang terdiri daripada akuiti visual, pembiasan, ujian katup, pemeriksaan luar okular dan pemerhatian tingkah laku kanak-kanak telah dijalankan. Empat kanak-kanak telah dikenal pasti berdasarkan pengiraan saiz sampel dan memenuhi kriteria gangguan dwi deria daripada 44 kanak-kanak yang disaring. Min umur adalah 9.3 ± 2.9 tahun. Majoriti kanak-kanak adalah daripada etnik India. Kategori 'deafblindness' adalah jenis kongenital dengan rubella sebagai penyebab utama. Semua kanak-kanak adalah bayi pramatang tetapi mempunyai berat lahir normal. Profil pendengaran menunjukkan majoriti mereka mengalami kehilangan pendengaran dua hala dengan min 'pure tone average' (PTA) antara 50 dBHL dan 120 dBHL. Punca utama masalah pendengaran ialah sensorineural dan majoriti kanak-kanak mempunyai alat bantuan pendengaran. Profil visual kanak-kanak 'deafblindness' menunjukkan sama ada persepsi cahaya (LP) dan dikategorikan sebagai miopia buta atau

aras rendah hingga sederhana. Majoriti mempunyai esotropia. Semua kanak-kanak menggunakan braille sebagai alat bantu visual dan kanak-kanak dengan penglihatan residual menggunakan televisyen litar tertutup (CCTV). Kaedah taktil adalah cara utama untuk komunikasi dan majoriti kanak-kanak menggunakan tongkat putih. Penilaian sikap dan pemerhatian luaran bersetuju dengan gangguan pendengaran dan penglihatan yang diwujudkan. Kualiti hidup dalam subjek ini adalah lebih rendah dalam 7 daripada 8 dimensi SF-36 berbanding dengan nilai normatif. 'Deafblindness' kongenital adalah kategori utama yang ditunjukkan oleh kanak-kanak dalam kajian ini di mana mereka mempunyai penglihatan yang teruk dan kehilangan pendengaran. Kaedah taktil adalah cara komunikasi utama bagi kanak-kanak ini. Kualiti kehidupan mereka telah terjejas dan dengan memperkenalkan pemulihan 'deafblindness' yang merangkumi gabungan pendengaran dan pemulihan penglihatan, diharapkan akan dapat membantu mereka dalam menjalani aktiviti harian mereka.

Kata kunci: Gangguan dwi-deria; kecacatan penglihatan; penglihatan terhad; kecacatan pendengaran; kualiti hidup; pemulihan

INTRODUCTION

Dual sensory impairment or deafblindness is a condition where concomitant hearing and visual impairments occur. The combination of these two impairments causes severe communication, developmental, and other educational deficits in this population that cannot be accommodated in existing special education programs designed solely for children with deafness or children with blindness. Dual sensory impairment can affect growth development in children in the areas of physical, cognitive, emotion, social and motility development (Smith et al. 2008). Prevalence of deafblindness in children is rare, reportedly between 0.53 to 1.8 in 10,000 children and the majority of cases are described as congenital deafblindness (Dammeyer 2010; Wolsey 2017). It was also reported that the cases of deafblindness are increasing due to factors such as different other causes of deafblindness being newly identified, the age of child who is diagnosed as deafblind, the parent's education level and awareness of the problem and the family income level (Alsop et al. 2000). A previous study in the United Kingdom has reported that the quality of life of deafblind children is affected because of the dual sensory impairment (Muller 2006) and understanding the profile of deafblindness children is important to design and provide for an early intervention program (Muller 2006).

Coping with dual sensory impairment or deafblindness can be a challenging task for the children affected and also for their parents or caregivers. Early intervention programs for dual sensory impairment are still not well established in Malaysia. Most available rehabilitation programs are focused on a single sensory impairment i.e. hearing impairment (Smith et al. 2008) or vision impairment (Omar et al. 2007; The National Consortium on Deaf-Blindness 2008; Omar et al. 2008). However, currently only limited information is available on the profile and quality of life information of dual sensory impairment or deafblindness among children in Malaysia. Hence the objective of this study is to determine the profile and quality of life for children with deafblindness who are enrolled in visually impaired special centres. It is hoped that with the information available, a better rehabilitation program can

be designed for children with dual sensory impairment or deafblindness in Malaysia.

EXPERIMENTAL METHODS

SUBJECTS

This was a prospective study and purposive sampling was adopted. This sample size calculation was based on the formula from Kish (1965) with the estimation prevalence of deafblind being 0.0032 (obtained from The National Centre on Deaf-Blindness 2008). Sample size calculation is as below:

$$\eta = \frac{z^2 p(1-p)}{\Delta^2} \quad (1)$$

$z = 1.96$ at significance level 0.05, $p =$ prevalence, $\Delta =$ margin of error vision assessment. The calculated sample size obtained for this study was 4 children diagnosed with deafblindness. Children with dual sensory impairment from two visually impaired rehabilitation centres were invited to take part in the study. Permission to conduct this research was granted by the principals of these two visually impaired rehabilitation centres and informed consent was also received from the parents. All personal identification details of each child selected for this study was kept confidential and remained anonymous. This research project was approved by the Universiti Kebangsaan Malaysia (UKM) Human Subject Ethics Committee, UKM 1.21.3/244/NN2018026, and followed the tenets of Declaration of Helsinki. The information extracted was demographic data such age and gender, ethnicity, category and cause of the deafblindness, birth weight, birth week, level of parent's education and income. Hearing loss information was extracted from the medical records such as type of hearing problem, level of hearing loss hearing threshold and hearing aid possession were also recorded.

Vision assessment including visual acuity, refraction, cover test, external ocular examination and children's behaviour observations were conducted on the deafblind children at the visually impaired rehabilitation centres. Visual acuity was taken using a LogMAR chart at 3 metres

with subjects' best correction being worn. Refraction was done on subjects using retinoscopy to determine the refractive error of the subjects. Cover test was done to determine any deviation of eyes or tropia in the subjects.

THE QUALITY OF LIFE SURVEY

The parents of potential participants were contacted either by telephone or when they visited the clinic and were invited to participate in the study. After consent was obtained, a copy of the Malay version of the Short Form (SF-36) questionnaire was given to the parents to obtain information on their child's quality of life. The SF-36 consists of 36 items that are employed to calculate scores on eight dimensions which are 1) physical functioning, 2) role limitation due to physical health problems, 3) bodily pain, 4) general health, 5) vitality, 6) social functioning, 7) role limitation due to emotional health problems, and 8) mental health. The scores for each dimension had a range of between 0 and 100, with a higher score indicating a better health related quality of life.

RESULTS

DEMOGRAPHIC, HEARING AND VISUAL IMPAIRMENT PROFILE OF DEAFBLIND CHILDREN

Four children were identified who fulfilled the dual sensory impairment criteria out of the 44 children screened at the visually impaired special centres. The mean age of children with dual sensory loss was 9.3 ± 3.3 years old. One child was from the preschool age group (≤ 6 years), two from the primary school age group (≤ 12 years) and one from the secondary school age group (≥ 13 years). Most of the children were of Indian ethnicity followed by Malay and Chinese ethnicities. It was also found that equal numbers of deafblindness occurred between male and female children in this study. The deafblindness categories were, congenital deafblindness with rubella as the main cause, followed by CHARGE's Syndrome and a rare birth defect named agenesis of the corpus callosum (ACC) (Table 1). The mean birth week was 36.3 ± 0.5 weeks and they had a normal birth weight with the mean weight being 2.8 ± 0.1

TABLE 1. Demographic, hearing and visual impairments profile of deafblindness children

Deafblindness Profile	Subjects			
	A	B	C	D
Demographic				
Age	11	13	7	6
Gender	Male	Male	Female	Female
Ethnicity	Indian	Chinese	Indian	Malay
Category	Congenital	Congenital	Congenital	Congenital
Causes	Rubella	Rubella	CHARGE's Syndrome	Agenesis of the corpus callosum
Birth Weight (Kg)	2.8	2.7	2.8	3.0
Birth Week	36	36	36	37
Parent's Education Level	High School	High School	High School	High School
Family Income	RM2000.00	RM2000.00	RM2000.00	RM2000.00
Hearing impairment Cause	AuditoryNeuropathy	Sensory Neural	Mixed	Sensory Neural
Hearing Threshold (dBHL)	AD: 90 AS: 90	AD: 50 AS: 50	AD: 120 AS: 120	AD: 120 AS: 120
Hearing Performance Classification	Profound	Moderate	Profound	Profound
Hearing Aids	Yes	No	Yes	Yes
Vision impairment Cause	Bilateral Cataract	Bilateral Cataract	Choroidal Coloboma	Bilateral Anophthalmia
Distance visual acuity (VA)	Light Perception	6/120	Light Perception	No Light Perception
Prescription of glasses (Ds)	RE: -2.00 LE: -2.50	RE:-1.50 LE:-1.00	RE: -3.00 LE:-4.50	-
Visual Performance Classification	Blind	Severe Low Vision	Blind	Blind
Cover Test	Esotropia	Esotropia	Esotropia	-
Visual Aids	Yes	Yes	Yes	Yes
Types of Aids	Braille	CCTV Braille	Braille	Braille
Mobility Aids	No	No	White Cane	White Cane
Types of Communication	Tactile	Tactile Tracking	Tactile	Tactile

AD – Right Ear RE – Right Eye CCTV – Closed Circuit Television for reading purposes
AS – Left Ear LE – Left Eye

kg. With regards their socio-economic status, all the parents had completed high school education and their income was from RM2000.00 to RM3000.00 per month.

The hearing profile showed that the majority of the deafblind children had profound bilateral hearing loss with one child had moderate bilateral sensorineural hearing loss. The hearing level was based on the pure tone average of 0.5, 1.0 and 2.0 kHz for the deafblind children in this study and ranged from 50 dB HL to 120 dB HL (Table 1). The main type of hearing problem was sensorineural which involved half of the children. Majority of the children did own hearing aids except for the child who had moderate hearing impairment.

For the vision impairment (Table 1), the majority of the children had visual acuity of light perception (LP) and are categorised as blind in the WHO Classification of Visual Performance 2017. One child had severe low vision with some useful vision, which was found to be 6/120. The types of refractive errors identified were low to moderate myopia where the mean power was -2.2 ± 0.8 Ds and -2.7 ± 1.8 Ds for right and left eyes respectively. Three children had esotropia while one of the children was diagnosed with bilateral congenital anophthalmia. The main cause of vision impairment was cataract, which was related to the Rubella infection they were afflicted with in utero. All the children were using braille as part of their visual aids. One severe low vision child used a specific low vision

aid called a Closed Circuit Television (CCTV) device to maximise his useful vision. Most of the children used mobility aids i.e. a white cane to travel independently. In terms of communications, all the children used tactile methods to communicate and the severe low vision child used an extra method to aid his communication i.e. tracking method to assist in his daily activities.

DEAFBLIND CHILDREN BEHAVIOUR OBSERVATION AND EXTERNAL EYE OBSERVATION

This assessment was conducted for the children in terms of observation of their behaviour and also an external eye observation (Table 2). It was found that during behaviour observation, a majority of the children had head tilt when gazing at distant objects, they constantly fell down, tripped over or bumped into objects and did not like to play games that involved distance viewing. Other behaviours frequently observed among these deafblind children included their face turning to one side when gazing at distant objects and constant blinking. In the external eye observation assessment, it was found that droopy and red eyes were among the common findings observed in the deafblind children. These children also showed signs of having eye discharge, white pupils, different coloured iris on the both eyes and distorted iris and pupil. One of the children also showed microphthalmia.

TABLE 2. Children behaviour observation and external eye observation

Behaviour Observation	Number/ (%)
Face turns when looking at distant objects	2/ (50)
Constant blinking	2/ (50)
Constant rubbing of the eye	0/ (0)
Head tilts when looking at distant objects	4/ (100)
Constantly falling down, tripping over or bumping into things	4/ (100)
Reading at a very close distance	0/ (0)
Squinting the eyes when looking at distant objects	0/ (0)
Closing one eye when looking at distant objects or in a bright condition	0/ (0)
Constant frowning	0/ (0)
Does not like to play games that needs distance viewing	4/ (100)
External Eye Observation	
	Number/(%)
Swelling around the eyes	1/ (25)
Tearing	0/ (0)
Discharge	2/ (50)
Droopy eyes	4/ (100)
Red eyes	4/ (100)
Growth on the sclera	0/ (0)
Distorted iris	1/ (25)
Different colour iris in of the right and left eye	2/ (50)
Distorted pupils	1/ (25)
White pupils	2/ (50)
Others	0/ (0)

QUALITY OF LIFE IN DEAFBLIND CHILDREN

The mean scores of the eight dimensions from the SF-36 are presented in Figure 1. For each of the dimensions (Figure 2), the participant's scores are observed lower than the normative value except for the vitality dimension. The vitality or energy dimension in deafblind subjects was higher than the normative value with mean score of $71.3\% \pm 2.2$ and $52.2\% \pm 22.4$, respectively. All participants had 0% score for role limitation due to emotional and physical health problem dimensions. These two dimensions were

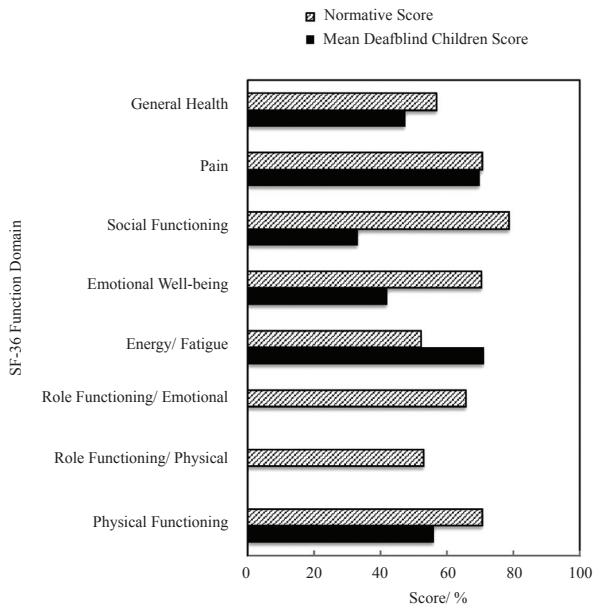


FIGURE 1. Normative and mean deafblind children SF-36 quality of life questionnaire scores

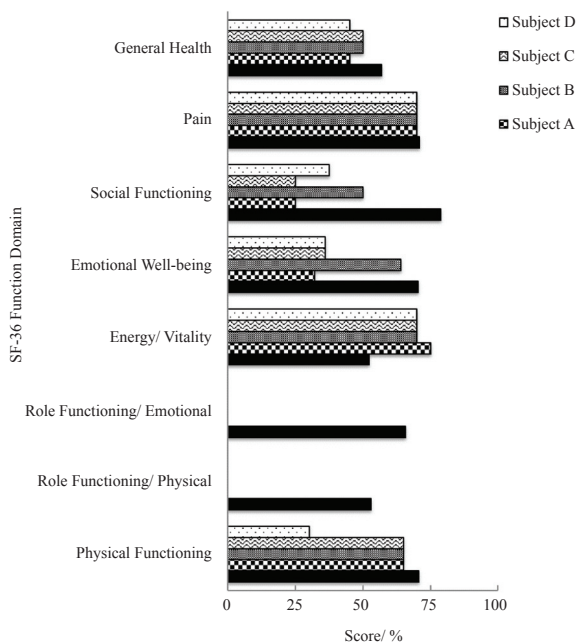


FIGURE 2. Normative and mean for each deafblind child's SF-36 quality of life questionnaire scores

found to be significantly lower than the norm ($p = 0.05$) (Table 3).

TABLE 3. Median, interquartile range and p-value of deafblind children SF-36 quality of life questionnaire scores based on binomial test (non-parametric test)

Domain SF-36	Median \pm IQR	p-Value
General health	47.5 \pm 5.0	0.06
Pain	70.0 \pm 0.0	0.07
Social functioning	31.5 \pm 22.0	0.06
Emotional well-being	36.0 \pm 24.0	0.07
Energy/ Vitality	70.0 \pm 3.8	0.06
Role functioning/ Emotional	0.0 \pm 0.0	0.05*
Role functioning/ Physical	0.0 \pm 0.0	0.05*
Physical functioning	65.0 \pm 26.3	0.59

*significant

DISCUSSION

The present study provides information about the demographics, sensory variables and quality of life of paediatric persons with deafblindness. There was no separate database for children with deafblindness available in the public domain, therefore we had to scrutinize all data available at the two rehabilitation centres. However, it was found that there were only four subjects who fulfilled the criteria and agreed to participate. This very small sample size is because congenital deafblindness is rare (Möller 2003). For example, Dammeyer (2010) found the prevalence of deafblindness among children in Denmark was 1 in 19 000.

The current study found an equal number of male and female subjects with deafblindness. The National Centre on Deaf-Blindness (2018) suggested that both genders have the same probability to have deafblindness. The current study also found that deafblindness can occur in any of the common ethnicities in Malaysia. There is however, no overview data available of the prevalence of congenital deafblindness among ethnicities in Malaysia. The National Centre on Deaf-Blindness (2008) found that the percentage of White-American (non-Hispanic) who had deafblindness was higher (59%) than non-Whites (39%) (The National Consortium on Deaf-Blindness, 2008).

Our findings showed that all four subjects had congenital deafblindness. There were two subjects with congenital deafblindness resulting from the Rubella infection syndrome. In this study, the other causes of congenital deafblindness were CHARGE syndrome and Agnesis of the Corpus Collosum. Previous research has shown that Rubella and CHARGE syndrome were some of the most common causes for congenital deafblindness (Gale 2008; The National Consortium on Deaf-Blindness 2008). In contrast, Dammeyer (2010) found Rubella was no longer the most common cause for congenital deafblindness among children in Denmark. Study by Dammeyer (2010) believed that the changes in the aetiology of deafblindness

could be attributed to the introduction of an immunization program against the Rubella virus.

All except one subject was diagnosed with profound hearing loss in this study. The type of hearing loss varied and included auditory neuropathy, sensorineural and mixed hearing loss. Based on the National Consortium on Deaf-Blindness United States (2008), the severity of hearing loss among the deafblind children can vary from mild to profound hearing loss. According to their data, the majority of deafblind children had sensory-neural hearing loss. They estimated that auditory neuropathy was present in about 1% of the 10, 174 children in their database. However, these findings need to be interpreted with caution, as about 74% of the data was incomplete in the database. The hearing severity of the participants in this current study required them to be fitted with an amplification device. Only one participant did not own a hearing aid. Although the rest of the participants owned hearing aids, the device however is hypothesised to be used only for sound awareness but not for communication. This is because none of the children used oral language as their method of communication

Looking at the vision characteristics in the deafblind children in this study, we found that most of the deafblind children had a refractive error, which was myopic, and most had ocular misalignment where their eyes were deviating inward. Most of the deafblind children were blind and this resulted in most of them are using low vision aids such as Braille. In addition, most of the deafblind children had certain behavioural traits such as frequently falling down, tripping over or bumping into objects and did not like playing games that required distance viewing. However, we were unable to identify any researchers studying the characteristics of vision in deafblind children.

Our findings showed that deafblind children had difficulty in almost all aspects of measured quality of life. Deafblind children are known to isolate themselves from involvement in social activities (White 2014). This could be due to their limitations in communication and mobility that hinder them from participating in social events (Crews & Campbell 2004). Kerstin (2003) also mentioned that physical functioning and general health of deafblind children declined at a faster rate than normal people. Thus, comprehensive management and intervention for deafblind children is necessary to reduce the impact of the condition on their quality of life.

The main challenge in this study was that it was difficult to ensure that all the subjects would cooperate with researcher while conducting the examinations needed on the subjects. The researcher needed to make time for subjects, as tasks took longer to complete as well as having to remind the subjects in the group constantly of the instructions they had to follow. To overcome these challenges, parents or care taker is assisted in the data collection process especially during the examination period. A further study of the types of communication needed among the deafblind children is required in order that for a model of a suitable rehabilitation program to be developed.

CONCLUSION

Profiling of dual sensory impairments or deafblindness in children provides a clearer picture and understanding of their condition. Congenital deafblindness is the main category in which these children had profound vision and hearing losses. Tactile methods were the main means of communication with these children. Their quality of life was found to be affected and introducing deafblindness rehabilitation, which includes a combination of hearing and low vision rehabilitation, is seen to be able to assist these persons afflicted in coping with their daily activities.

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