BioMed Research Journal
BMRJ, 3(1): 69-74
www.scitcentral.com

ISSN: 2578-8892

Original Research Article: Open Access

Deaf Mutism Population and Quality of Life Measure for Adolescents with Deaf Mutism in Bengkala Village and Deaf School

Eka Putra Setiawan[1], Komang Andi Dwi Saputra[1], I Made Muliarta[2] and Putu Mayestika Sesarini[1]

*[*1]Department of Otorhinolaryngology, Medical Faculty of Udayana University, Sanglah Hospital, Denpasar, Indonesia*
[2]Physiology Department, Medical Faculty of Udayana University, Denpasar, Indonesia.

Received March 28, 2019; Accepted April 16, 2019; Published April 27, 2019

ABSTRACT

Background: Deaf mutism can affect the development of speech, social, cognitive and academic abilities. Adolescence is the stage of life with rapid developmental changes, the concept of quality of life (QoL) is important to understand for adolescents who experience hearing loss because of the importance of communication and social participation in everyday life. Bengkala village in Bali, Indonesia, has a population of deaf mutism of 44 individuals in 3.032 inhabitants or around 1.4%, is caused by recessive gene mutations at the DFNB3 locus. The aim of this study is to find out whether there are differences in the QoL of deaf mutism adolescents in Bengkala and deaf school as control.

Method: This study is an observational analytic study using cross-sectional design. The subjects in this study were deaf mutism adolescents in Bengkala and who attended deaf school as many as 22 people. The Youth Quality of Life Instrument – Deaf and Hard of Hearing (YQOL-DHH) questionnaire was filled in with three domains, namely self-acceptance, stigma and participation.

Results: From the results of the independent t-test, the average QoL based on self-acceptance in Bengkala was 129.8 ± 2.5 while in deaf school was 88.7 ± 15.1. The mean QoL based on stigma in Bengkala was 35.1 ± 6.6 while in deaf school was 38.2 ± 4.2. The mean QoL based on participation in Bengkala was 68.9 ± 2.6 while in deaf school was 55.6 ± 10.0.

Conclusion: The quality of life of adolescents with deaf mutism in Bengkala village and deaf school based on of self-acceptance and participation found significant differences with significance values, while stigma was not statistically significant.

Keywords: Deaf mutism, Adolescents, Quality of life, Bengkala

INTRODUCTION

Hearing loss at a young age results in delays and difficulties in speech and language development. One cause of hearing loss at a young age is congenital deafness, which is deafness that occurs in individuals due to factors that affect pregnancy and at birth. Deafness usually occurs in the form of severe to profound sensorineural deafness in both ears [1]. Genetic is the most common cause of deafness where there are 2 forms of deafness, namely syndromal deafness (70%) and non-syndromic [2]. The prevalence of deaf births in the world is around 1-3 cases in 1000 births. In America, the prevalence is 0.1% birth [3]. The Indonesian health profile in 2005 predicts that there are 214,100 deaf people out of 214,100,000 Indonesian citizens and this number increases every year due to high birth rates [4].

Bengkala village is one of the villages in Kubutambahan district, Buleleng regency, Bali, Indonesia, has a population of deaf people with as many as 44 individuals in 3,032 inhabitants or around 1.4%. They are referred to as *kolok*, which means they cannot hear in Balinese. Winata et al. [5] using the DNA (Deoxyribonucleic acid) Short Tandem Repeat method, found that there was a recessive gene mutation at the DFNB3 locus on chromosome 17. Therefore the type of deafness that is owned by Bengkala villagers is an autosomal recessive non-syndromal hearing disorder. The results of the study also estimated that DFNB3 had appeared in the gene pool of Bengkala villagers from 150-300 years ago. According to Lestari and Luthfiana [6], the community in Bengkala has created social cultural inclusion for deaf mutism as part of a community that also has a role in

Corresponding author: Eka Putra Setiawan, Department of Otorhinolaryngology, Medical Faculty of Udayana University, Sanglah Hospital, Denpasar, Indonesia, E-mail: ekaputra.tht@gmail.com

Citation: Setiawan EP, Saputra KAD, Muliarta IM & Sesarini PM. (2019) Deaf Mutism Population and Quality of Life Measure for Adolescents with Deaf Mutism in Bengkala Village and Deaf School. BioMed Res J, 3(1): 69-74.

community life. Deaf mutism in Bengkala does not make their shortcomings a problem in terms of getting an education and getting a job.

Adolescence is a stage of life with rapid developmental changes, but little is known about how these changes affect the quality of life (QoL) of adolescents with hearing loss. Patrick et al. [7] from the University of Washington developed an instrument Youth Quality of Life Instrument-Deaf and Hard of Hearing (YQOL-DHH) which has been validated and widely publicized. This questionnaire consists of 3 dimensions that reflect the important aspects of the lives of adolescents with hearing loss, namely self-acceptance, participation and perceived stigma. Measuring how their QoL can provide children, parents, and physicians important information that can help guide individual and social choices to optimize subjective well-being [8]. Research comparing the community of deaf teenagers has never been done. Therefore the authors are interested in knowing whether there are differences in the quality of life of deaf mutism adolescents in Bengkala Village compared to deaf school students.

METHOD

This research method is analytical research with cross sectional study approach. Research location in Bengkala village and one of deaf school in Bali, Indonesia. Pure tone audiometry is performed on all deaf mutism to find out the hearing threshold. The study population was deaf mutism aged 11-18 years who lived in Bengkala and attended deaf school during the study period in December 2018 to January 2019. Inclusion criteria are deaf mutism aged 11-18 years, living in Bengkala and attending deaf school, willing to complete the questionnaire completely. Exclusion criteria are patients with other syndromal disorders such as Down's syndrome, Usher's syndrome and others. Data collected were analyzed statistically using SPSS version 2.4 for Windows computer software. The descriptive analysis of the study included the presentation of the results descriptively using numerical and categorical data. Normality test using Shapiro-Wilk test was obtained, the data were normally distributed, then continued with independent-t test.

RESULTS

Deaf mutism in Bengkala village numbered 44 people and pure tone audiometry was performing to find out the hearing threshold in 43 people. One person was under 7 years old and performed Brainstem Evoked Response Audiometry (BERA) for diagnostic **(Table 1)**.

Table 1. Characteristics and hearing threshold of mute deaf people in Bengkala village.

Variables	Frequency	Percentage (%)
Age range		
0-15	7	15.91
16-25	6	13.66
26-40	7	15.91
41-50	14	31.82
51-74	10	22.73
Sex		
Male	19	43.18
Female	25	56.82
Hearing Threshold		
Mild	0	0
Moderate	0	0
Moderate-Severe	0	0
Severe	0	0
Profound	44	100

The sample was 11 deaf adolescents in Bengkala and 11 deaf school students who met the inclusion criteria, this number corresponded to the minimum number of samples, which were 11 subjects. Data was collected by filling out the YQOL-DHH questionnaire **(Table 2)**.

Table 2. Characteristics of research samples (n=22).

Variables		Group	
		Bengkala (n=11)	**Deaf School (n=11)**
Age (year)			
Average ± SD		15.6 ± 2.5	16.5 ± 1.3
Sex			
Male		5 (45.5%)	6 (54.9%)
Female		6 (54.9%)	5 (45.5%)
Graduated/was in school			
Yes		11 (100%)	11(100%)
No		0 (0%)	0 (0%)
Job Status			
Work		5 (45.5%)	0 (0%)
Not work		6 (54.9%)	11 (100%)
Marital Status			
Married		5 (45.5%)	0 (0%)
Unmarried		6 (54.9%)	11 (100%)
Parent Hearing Status			
Mother	Hearing	3 (27.3%)	11 (100%)
	Deaf	8 (72.7%)	0 (0%)
Father	Hearing	3 (27.3%)	11 (100%)
	Deaf	8 (72.7%)	0 (0%)

Based on the independent t-test it was found that the difference in QoL based on self-acceptance was significant with a significance value of p<0.001 (p<0.05) and based on meaningful participation with a significance value p=0.001 (p<0.05). As for the stigma, no significant difference was found with a significance value of p=0.207 (p>0.05) **(Table 3)**.

Table 3. Comparison of the average QoL of Bengkala and deaf school groups based on self-acceptance, stigma and participation.

Variables	Group		Average different	95% Confidence Interval	P-value
	Bengkala (n=11) Average ± SD	**Deaf school (n=11) Average ± SD**			
Self-acceptance	129.8 ± 2.5	88.7 ± 15.1	41.1	30.9-51.3	<0.001
Stigma	35.1 ± 6.6	38.2 ± 4.2	-3.1	-8.0-1.9	0.207
Participation	68.9 ± 2.6	55.6 ± 10.0	13.5	6.7-20.4	0.001

DISCUSSION

In this study, deaf mutism in Bengkala Village were 44 people, 19 male (43.18%) and 25 female (56.82%), the majority of hearing impaired people were 41-50 years old as many as 14 people (31.82%), while the lowest is in 2 age groups, 16-25 years are 6 people (13.66%). The hearing threshold of all deaf population is profound (100%).

Characteristics of research sample

Samples in Bengkala numbered 11 people aged 12-18 years, male as much as 45.5% and female 54.5%. While the sample in deaf school was 11 people with ages ranging from 15-18 years, male were 54.5% and female were 45.5%. Based on the level of education, all samples in Bengkala were in school, i.e., 3 people were attending an inclusive elementary school in Bengkala and 8 were elementary school graduates and did not continue to the next level due to various reasons. All samples at deaf school are attending school at the junior high school and high school. The research in the United States about the QoL of adolescents with severe to profound sensorineural hearing loss followed by adolescents as many as 157 people aged 11-18 years (mean age 14.1 years) with male gender as much as 47.7% and female 52.3%. All research subjects are currently taking various levels of education both in public schools, inclusive schools and deaf schools.

Samples in Bengkala were 5 people who had worked with various types of work, including as photographers, farmers, and laborers, as well as 6 people who did not work, namely 2 housewives, 3 people were in school and 1 person had not worked. All samples in deaf school did not work because they were still in school. The marital status of research subjects in Bengkala was obtained by 5 married people and 6 unmarried people, while in deaf school all were not married. Research by Borujeni et al. [8] in Iran about the QoL of deaf mutism adolescents followed by non-worker and unmarried adolescents who are still pursuing education in public schools, inclusive schools and deaf schools.

Based on the hearing status of the parents of the research subjects, in Bengkala it was obtained from the mother or from the father's side as many as 3 people could hear and 8 people did not hear, while in the deaf school from the mother or other parties (100%) could hear. The hearing statuses of parents of subjects are parents who heard as much as 84.7%, one parent who was not seen as much as 5.1% and both people who did not hear as much as 9.0% and 2 samples did not know the hearing status of their parents. Winata et al. [5] in Bengkala found that there is a recessive gene mutation that is needed for the birth of individuals with hearing loss. This is due to local endogamy carried out by deaf mutism in Bengkala from generation to generation.

Differences in mean QoL based on self-acceptance

Accepting self-condition, especially physical condition and being able to use it effectively is one form of adolescence adjustments at the stage of human development. Hurlock [9] states self-acceptance as a level at which a person has considered his characteristics feels capable and is willing to live with those characteristics.

Ebahimi et al. [10] states that the birth of a child with deafness is a stressful and unpredictable life experience for parents. In general, around 90% of children with deafness are born from normal hearing parents, this is consistent with this study in the deaf school subject group, which is 100% having normal hearing parents. Khotimah [11] states that if parents, especially mothers, accept the condition of the child, it will be able to help in care and will support children's development. The results of her research show that the picture of acceptance shown by the subject, namely the existence of realistic expectations of the situation, confidence in his standards, has a calculation of limitations on himself, aware of his own assets and realize the shortcomings. Wasito et al. [12] found that people with deaf mutism from deaf parents also showed relatively better social maturity than deaf people from hearing parents. Local endogamy carried out by deaf mutism in Bengkala caused most parents of deaf mutism adolescents also be deaf and mute. Parents consciously choose couples who are both deaf and have prepared themselves and surrender/accept if someday will give birth to deaf descendants as well.

In Bengkala there is an inclusive school that aims to provide opportunities for deaf mutism students to learn about diverse friends, not only fellow students, and have the potential to provide social support so that social competencies including adaptability will develop and will later make them ready to be involved on normal activities in the wider community[13]. This is in accordance with the opinion of Fellinger [14], where deaf mutism children have lower psychosocial problems when in inclusive schools compared to when in deaf school. This opinion is also supported by research conducted by Alwis [15] that when deaf mutism students study in inclusion schools, they have good adaptation because their peers and teachers interact well with them. While when at deaf school, deaf mutism students do not interact with hearing students during the learning process at school because in deaf school students with special needs learn together with students with special needs who have the same specificity as him.

In addition to the conditions previously explained, the community of Bengkala has a unique thing, namely the belief of Bhatara Bongol (Deaf God) as one form of public perception about deafness experienced by local residents. This belief has been preserved for hundreds of years and is followed by historical relics that have been discovered and studied [16]. The existence of these beliefs also creates a

sense of accepting/surrender to the condition of their deafness that has been experienced for generations.

Difference in mean QoL based on stigma

Donaldson [17] said that individuals who are stigmatized may have their own beliefs about how other people's judgments or feelings towards the condition of stigma exist in themselves and then internalize those judgments. So that it can be said that when someone experiences interaction or negative treatment from others, it will form perceived stigma, meaning that individuals form their own perceptions about how other people's judgments or feelings toward him or her are affected by stigma and internalize that stigma towards him.

Hurlock [9] suggests one condition that causes adolescents not to get social acceptance is the lack of maturity, especially in controlling emotions, calmness, confidence and wisdom. In general, these conditions eventually make deaf mutism will look for deaf mutism fellow also in a closer relationship. This condition also occurs both in Bengkala and in the other areas, including in deaf school that have dormitory facilities. This is also consistent with the statement by Santrock [18], that individuals from minorities, in this case deaf mutism, consider relations with peers who also come from minorities will give feelings of brothers who are very important and reduce isolation in themselves the individual.

Batten et al. [19] stated that deaf mutism adolescents may be delayed in communication and social skills due to limited communication experience from the beginning. The experience of communication as early as possible is very important, because without it dumb deaf teenagers may struggle to develop theories that are appropriate to the age of thought and social competence, which in turn can negatively impact the development of communication and maintain their self-stigma thereby reducing further opportunities communication and social skills.

Differences in mean QoL based on participation

Leary [20] states that social acceptance means that there is a signal from other people who want to include someone to join a relationship or social group. Social acceptance occurs starting from tolerating the presence of others to actively wanting someone to be a partner in a relationship. Social acceptance is one of the factors that influence a person's participation. Participation is the active involvement of someone in responding to activities and supporting the achievement of goals and being responsible for their involvement.

Youth groups in Bali have their own place in the social environment. In each village consisting of several banjar (groups), they have an association called Sekaa Teruna Teruni (STT) and consist of unmarried teenagers. Research by Kurniati et al. [21] in Bengkala regarding the understanding and acceptance of STT members towards deaf mutism stating that all STT members both men and women received well the presence of deaf mutism in their area. Their form of acceptance is by including deaf mutism adolescents in STT, making friends, and involving them in several activities in their village. The activity that they often do together is during mutual cooperation in preparing religious ceremonies at the temple. They stated that they were not ashamed to be friends with the deaf mutism and highly valued them as individuals who were diligent in their work. Deaf mutism adolescents are given preferential treatment in the form of discharge from all obligations such as organizational contributions.

An environment that can accept deaf mutism will make individuals easily make adjustments to other people and have great motivation for their future. Conversely, if the environment cannot accept it, what will happen is that the individual becomes isolated and closes himself in his social environment. This environmental influence causes deaf mutism to be difficult to do social interaction with other people either personally or in groups, making individuals tend to be happier to get along with their communities, namely deaf mute communities [19].

The local wisdom of Balinese culture such as the Tri Hita Karana concept can be adapted in today's social life, especially in the area/environment with a diverse composition of society, including people with disabilities; in this case the person is deaf and mute. The concept of Tri Hita Karana as the basis for gaining happiness in life which is essentially a balanced attitude between worshiping God and serving others and developing compassion for the environment. In this context the emphasis is on human relations that have been well implemented in Bengkala, such as the spirit to mingle, communicate and cooperate with all citizens, both normal hearing and deaf mutism residents. The community in Bengkala has created social cultural inclusion for deaf mutism as part of a community that also has a role in community life [6]. They are accepted in their families and in the community and are given full rights and responsibilities in the village. They participate fully and are active in all areas and lives of the community. This social life in Bengkala also reflects the implementation of Pancasila as the basis of the Indonesian state, especially the principle of just and civilized humanity and social justice for all the people of Indonesia.

CONCLUSION

The QoL between deaf mutism adolescents in Bengkala Village and deaf school based on self-acceptance and participation statistically found differences, while the QoL based on stigma was not statistically different.

ACKNOWLEDGEMENT

Author(s) received no specific funding for this work.

REFERENCES

1. Steer CD, Bolton P, Golding J (2015) Preconception and prenatal environmental factors associated with communication impairments in 9 year old children using an exposome-wide approach. PLoS One 10: 23-25.
2. Sivakumaran TA, Husami A, Kissel D, Zhang W, Keddache M, et al. (2013) Performance evaluation of the next generation sequencing approach for molecular diagnosis of hereditary hearing loss. Otolaryngol Head Neck Surg 146: 1007-1016.
3. Gurtler N (2008) Hereditary hearing impairment. In: Lalwani AK; Current Diagnosis and Treatment in Otolaryngology Head and Neck Surgery. USA: The McGraw Hill, pp: 697-704.
4. Soetjipto D (2016) Komite Nasional Penanggulangan Gangguan Pendengaran dan Ketulian. Available at: http://komnaspgpkt.blogspot.com/
5. Winata S, Arhya IN, Moeljopawiro S, Hinnant JT, Liang Y, et al. (1995) Congenital non-syndromal autosomal recessive deafness in Bengkala, an isolated Balinese village. J Med Genet 32: 336-343.
6. Lestari W, Luthfiana Y (2013) Orang kolok dan orang inget: Studi kasus tentang inklusi sosial difabel ketulian dan penanganan kesehatan indera di Desa Bengkala, Buleleng, Bali. Buletin Penelitian Sistem Kesehatan 15: 1-7.
7. Patrick DL, Edward TC, Skalicky AH, Schick B, Topolski TD, et al. (2011) Validation of quality of life measure for deaf or hard of hearing youth. Otolaryngol Head Neck Surg 145: 137-145.
8. Borujeni SS, Hatamizadeh N, Vameghi R (2015) Hearing loss related quality of life in adolescents with hearing loss. Iran Rehabil J 13: 38-43.
9. Hurlock EB (2011) Psikologi perkembangan suatu pendekatan sepanjang rentang kehidupan. 5th Edn. Jakarta: Erlangga.
10. Ebrahimi H, Mohammadi E, Pirzadeh A, Shamshiri M, Mohammad A (2017) Living with worry: The experience of mothers with deaf child. Int J Pediatr 5: 42.
11. Khotimah N (2009) Penerimaan Ibu yang Memiliki Anak Tunarungu. Available at: http://www.gunadarma.ac.id/library/graduate/psychology
12. Wasito DS, Sarwindah D, Sulistiani W (2010) Penyesuaian sosial siswa tuna rungu di sekolah umum. Jurnal Psikologi Teori dan Terapan 2: 138-152.
13. Marthan, LK (2007) Manajemen pendidikan inklusif. Jakarta: Departemen Pendidikan Nasional.
14. Fellinger J, Halzinger D, Pallard R (2012) Mental health of deaf people. Lancet 379: 1037-1044.
15. Alwis C (2005) Children with hearing Impairment in regular classroom. Sri Lanka J Educ Res 9: 45-69.
16. Suarbhawa IGM, Sunarya IN (2009) Laporan Penelitian Arkeologi Survei Epigrafi Kubutambahan Buleleng. Denpasar: Balai Arkeologi Denpasar.
17. Donaldson P, Langham E, Best T, Browne M (2015) Validation of the gambling perceived stigma scale (GPSS) and the gambling experienced stigma scale (GESS). J Gambling Issues 31: 163-200.
18. Santrock WJ (2008) Psikologi Pendidikan. Jakarta: Prenada Media Group.
19. Batten G, Oakes PM, Alexander T (2013). Factors associates with social interactions between deaf children and their hearing peers: A systematic literature review. United Kingdom: Department of Clinical Psychological Therapies, The University of Hull.
20. Leary MR (2010) Affiliation, acceptance and belonging: The pursuit of interpersonal connection. Dalam: Fiske ST, Gilbert DT, Lindzey G (penyunting). Handbook of social psychology. Hoboken, NJ, US: John Wiley & Sons Inc., pp: 864-897.
21. Kurniati DPY, Suariyani NLP, Listyowati R, Mangunsong F, Pratomo H, et al. (2013) Pemahaman dan penerimaan anggota sekaa teruna teruni terhadap warga kolok di desa Bengkala, kecamatan Kubutambahan, Buleleng, Bali. Available at: https://simdos.unud.ac.id/