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PARENTAL EDUCATION ABOUT STIGMA AND DISCRIMINATION IN CLEFT LIPS AND PALATE PATIENT: A COMMUNITY EMPOWERMENT

Edukasi Orang Tua Tentang Stigma dan Diskriminasi Pada Pasien Celah Bibir Dan Langit-Langit: Pengabdian Masyarakat

Ruby Riana Asparini¹, Feby Alfina Damayanti², Erina Sofia Atha², Revi Ruli Pranita², Shabrina Adilia Roida²

¹Department of Surgery, Faculty of Medicine, Muhammadiyah Malang University

²Faculty of Medicine, Muhammadiyah Malang University

Correspondence author: Ruby Riana Asparini, ruby@umm.ac.id, Department of Surgery, Faculty of Medicine, Muhammadiyah Malang University

188Ath Bendungan Sutami street, Malang, Jawa Timur, Indonesia, 65144

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ABSTRACT

Background: Cleft lip and palate (CLP) is the second most common congenital craniofacial anomaly, with 1 in 600 births worldwide. Children with CLP are very vulnerable to stigma and discrimination. **Purpose:** Changes in parents' understanding of the stigmatization and discrimination experienced by families with children born with CLP. **Methods:** This was a cross-sectional descriptive study among parents of children born with CLP. Education about stigmatization and discrimination is given. Pre-test and post-test are also performed using an interviewer-administered questionnaire. The total score was analyzed using paired t-test. **Results:** The total score of parents' education on stigma and discrimination in CLP was initially 8.29 and increased to 9.39 after receiving education. The change in knowledge was statistically significant ($p = 0.029$). **Conclusion:** The education provided has been shown to have a positive impact on parents' understanding of the stigmatization and discrimination experienced by families with children born with CLP.

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ABSTRAK

Latar belakang: Celah bibir dan langit-langit (CBL) adalah anomali kraniofasial kongenital kedua yang paling umum, dengan 1 dari 600 kelahiran di seluruh dunia. Anak dengan CBL sangat rentan mengalami stigma dan diskriminasi. **Tujuan:** Perubahan pemahaman orang tua akan stigmatisasi dan diskriminasi yang dialami oleh keluarga dengan anak yang lahir dengan CBL. **Metode:** Merupakan studi deskriptif cross-sectional pada orang tua dari anak-anak yang lahir dengan CBL. Edukasi tentang stigmatisasi dan diskriminasi diberikan, pre-test dan post-test kemudian dilakukan dengan menggunakan kuesioner yang diberikan oleh pewawancara. Skor total dianalisis menggunakan uji t berpasangan. **Hasil:** Total skor edukasi orang tua akan stigma dan diskriminasi pada CBL awalnya 8,29 dan meningkat menjadi 9,39 setelah mendapat edukasi. Perubahan pengetahuan tersebut signifikan secara statistik ($p = 0,029$). **Kesimpulan:** Edukasi yang diberikan terbukti memberikan dampak positif terhadap pemahaman orang tua akan stigmatisasi dan diskriminasi yang dialami oleh keluarga dengan anak yang lahir dengan CBL

INTRODUCTION

Cleft lip and palate (CLP) is the second most common congenital craniofacial anomaly, with 1 in 600 births worldwide (Mossey et al., 2009). This is more apparent in low-middle-income countries. Children with CLP are very vulnerable to stigma and discrimination. Stigma is a negative characteristic attached to a person's personality due to the influence of his environment, while discrimination is the difference in the treatment of fellow citizens. The difference in treatment could be based on skin color, class, ethnicity, economy, religion, and so on, which has an impact on the fulfillment of that person's human rights. The negative stigma that causes acts of discrimination arises because of a person's negative perspective on a perceived difference (Chung et al., 2019). Children with CLP are particularly vulnerable to the psychosocial consequences of stigma and discrimination. Social stigma places these children at an additional disadvantage in education, work, and marriage. This stigma and discrimination can arise from family members, friends, community members, health workers, and even from family, in this case, parents (internalized stigma) (Kimotho & Macharia, 2020).

METHODS

Design: This was a cross-sectional descriptive study among parents of children born with CLP. Education about stigmatization and discrimination is given. The pre-test and post-test are also performed using an interviewer-administered questionnaire (Adeyemo et al., 2016). A questionnaire by Adeyemo et al. (2016) is replicated in the native language.

Outcome: Changes in parents' understanding of the stigmatization and discrimination experienced by families with children born with CLP

Sample: The population of this study was all parents who came to visit the CLP Center FKUMM from October to November 2021.

Data Analysis: Descriptive data is presented in the form of text and tables. The total score is analyzed using paired t-test.

RESULTS

Demographic data in this study found the average age of parents is around 31-32 years, with the majority having 2 children (64.29%) and the position of the child with CLP is the second child (64.29%). As many as 71.43% of their children have cleft lip and palate (See table 1).

Table 1 Demographic Data

Characteristic	Results
Age, mean ± sd	31.57 ± 7.661489
Number of children	
1	6 (21.43%)
2	18 (64.29%)
3	4 (14.29%)
Position of the child	
First	7 (25%)
Second	18 (64.29%)
Third	3 (10.71%)
Type of cleft	
Cleft palate	0 (0.00%)
Cleft lips	8 (28.57%)
Cleft lips and palate	20 (71.43%)

Data from the questionnaire that had been done by parents showed improvement after education about

stigmatization and discrimination is given. Positive changes in the percentage of answers are found in questions number 1,2,4,5,7 and 12 (see table 2).

The results of the total parental education score on stigma and discrimination in cleft lip and palate patients significantly increased after receiving education ($p=0.029$, $p<0.05$), which means that the education provided was able to change the parents' perception of stigma and discrimination in cleft lip and palate from bad to good (see table 3).

Table 2 Pre-test and Post-test Results of Questionnaire by Parents

Question	Pre-test Results (%)	Post-test Results (%)
What do you think is the cause of your child's cleft (deformity)?		
Another reason	32,14	10,71
Hereditary or environmental factors	28,57	67,86
God's will	35,71	17,86
Husband fishing	3,57	3,57
According to other family members/relatives/friends, what is the cause?		
Another reason	32,14	10,71
Hereditary or environmental factors	28,57	67,86
God's will	35,72	17,86
Evil spirit	0	0
Husband fishing	3,57	3,57
A pregnant woman laughing at a patient with cleft lip and palate	0	0
A pregnant woman going out at night	0	0
Cause of bad people	0	0
Are you ashamed to have this child?		
No	85,71	85,71
Yes	14,29	14,29
What was your immediate reaction when you had this baby?		
Abandon it in hospital/other birthplaces	3,57	0
Others	21,43	17,86
Seek help	75	82,14
Abandon baby	0	0
After the birth of this child and you see the defects, do you wish that this child was never born?		
No	75	85,71
Yes	25	14,29
Is your husband ashamed of this child?		
No	92,86	92,86
Yes	7,14	7,14
Is your sibling ashamed of this child?		
No	75	78,57
Yes	25	21,43
Is your friend ashamed of this child?		
No	77	77
Yes	25	25
Have you ever been treated as an outcast by your neighbors, relatives, and friends because of this child?		
No	71,43	71,43
Yes	28,57	28,57
Have friends, neighbors, or relatives ever refused to hold this child?		
No	82,14	82,14
Yes	17,86	17,86
Do you have reason to believe that your caregivers (doctors, nurses, medical records staff, etc.) are embarrassed by this child or treat you badly because of this child?		
No	92,86	92,86
Yes	7,14	7,14
What do you think health workers, communities, government, and media need to do to reduce the stigma (shame) regarding this kind of deformity?		
Any other suggestions	3,57	3,57

Awareness campaigns among mothers during the prenatal period	10,71	7,14
Public awareness about the causes and prevention of deformity	53,57	60,71
The role of the government in reducing the stigma associated with this condition	32,14	28,57

Table 3 Paired T-Test Analysis

Skor total	Mean \pm sd	P value
Pre-test*	8,29 \pm 2,29	0,029
Post-test*	9,39 \pm 1,57	

DISCUSSION

Cultural assumptions and beliefs about the causes of CLP can greatly impact affected individual and their family. Stigma and discrimination against people with CLP still persist. This encourages a community service in the form of providing parental education about stigma and discrimination in cleft lip and palate patients, which has been carried out on 30 parents with cleft lip and palate.

The education provided has a positive impact on parents' knowledge about stigma and discrimination against cleft lip and palate patients. This can be seen from the positive change in the percentage of answers to questions number 1,2,4,5,7 and 12, as well as from the results of significant statistical analysis.

Various limitations experienced by individuals with cleft lip and palate will produce various psychological difficulties. Impaired communication, for example, in individuals with cleft lip and palate does not appear to be the result of a phonological defect but of psychological problems that can affect the entire development of the affected child. Anxiety and depression have also been reported to be twice as common in adults with cleft lip and palate compared with normal adults (De Sousa et al., 2009).

The etiology of clefts is viewed as parental punishment, parental error, or parental personal behavior, including parental slips and falls, or collisions to the fetus' face. One parent believes their child's cleft is the result of the father cutting a fish's mouth when fishing while the mother was pregnant. Other causes are believed to include the effects of "God's will", supernatural powers, evil spirits or ancestral spirits, eclipses, black magic, or infectious diseases. Furthermore, children with CLP may not be seen as human. When asking the general public about clefts, very few know that it affects the lips and face, let alone its etiology (Chung et al., 2019).

Theorists from the symbolic interactionist tradition believe that the meaning of social objects, such as people and actions, is a social construct. Social constructionists hold their main assumption that in society, people developed their understanding and meanings during social interactions. Some of these social constructs are used to perpetuate stigma among members of different communities. Stigma is viewed as a distinct identity, meaning that a person is somehow abnormal or not accepted by society because of a physical disability, signs of "immoral" or inappropriate behavior, or membership in a particular group (Goffman, 2009).

Stigmatism communication, in particular, can be defined as the mechanism by which CLP stigma messages are created, amplified, and maintained through the communication process and how these messages propagate through the community to teach its members to recognize the reprehensible (i.e., recognize stigma) and react accordingly (Smith, 2007). When a community perceives a health condition as "appropriate punishment" for violating a cultural norm, they lack empathy for the condition of the people affected. This finding, therefore, corroborates previous research which has argued that cultural beliefs about health conditions or illnesses can lead to prejudice and social exclusion from stigmatized people (Kimotho & Macharia, 2020).

Parental education about stigma and discrimination in cleft lip and palate has been shown to change parents' knowledge. Parental education needed to continue to be carried out so that there is a change in parents' understanding, for the sake of improving the future of children with CLP.

CONCLUSION

The education provided has been shown to have a positive impact on parents' understanding of the stigmatization and discrimination experienced by families with children born with CLP.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest in this work

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