

Parents' Self Esteem of Children with Cleft Lip and Palate

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Abstract

Cleft lip and palate are congenital abnormalities that occur in children. Success in the management and treatment of this disorder requires the role of parents. However, often parents are embarrassed and have low self-esteem, so it would interfere with the success process of treatment and child care with clefts. This study aimed to determine the parents' self-esteem of children with cleft lip and palate in the Yayasan Pembina Penderita Celah Bibir dan Langit-langit (YPPCBL) Bandung. This research was a descriptive quantitative study. The study population was parents of children with cleft lip and palate. A total of 30 respondents participated in this study which was chosen with total sampling method. Parental self-esteem was measured using modified instruments based on Coopersmith's theory, with validity values of $r = 0.977$ and Cronbach's $\alpha = 0.989$. Data were analyzed using frequency distribution. The results showed 18 respondents (60%) had high self esteem and 12 respondents (40%) with low self esteem. This research would be an evaluation material for YPPCBL Bandung in maintaining and improving parents' self-esteem of children having clefts. With high self-esteem, it is potential for nurses to increase parental participation as a primary caregiver of children with clefts, it would also improve the success of care and children's quality of life.

Keywords: Cleft Lips and Palate, Parents, Self Esteem.

Introduction

Cleft lip and palate are the most common health problems in children around the world. In the UK the rate of cleft lip and palate was about 1 in 700 the number of live births (Mossey, Little, Munger, Dixon, & Shaw, 2009). In 2012, Lip and Palate Training Center notes Indonesia - the fourth highest populated country with a population of more than 249 million people - estimated that there were 7,500 children with cleft lip and palate per year (Kembaren, 2012; Davita, Narmada & Sudjana, 2014). Basic Health Research in 2013 recorded the prevalence of children aged 24-59 months who experienced cleft lip and palate in 2013 was 0.08%.

Baby with cleft lip and palate already had some problems as they could not suckle properly. Breastfeeding should be performed in right technique, such as the baby was given a pacifier or a special tool, in sitting position so that milk would not enter the nose, and the baby often burps (3-4 minutes). Babies needed to be encouraged to perform strong sucking reflexes, because sucking reflexes help them in developing speaking abilities. It is also important to maintain cleft clearance so that no residual milk formula, mucus, or foreign substances are present (Encyclopedia of Children's Health, 2017).

Patients with clefts also have psychological problems, because they felt they are different from others. Physically, the gap on the lips will cause difficulty in drinking due to weak sucking and a lot might spill or leak into the nose. In addition, there are problems on the aesthetic side, the development of incomplete teeth, disorders in the growth of the jaw, and speech disorders (nasal voice). Diseases that may also occur in patients with cleft lip and palate are infections in the middle ear to hearing loss (Soelarto, 1995; Marzoeki, 2002).

This disorder causes some interfere with the child's self-esteem and their parents. Parsons, Young, Parson, Dean, and Murray (2011), reported that mothers with children with cleft lip and palate would be less responsive than the ones with normal children. Children with cleft lip and palate are associated with various disadvantages in children, such as behavioral, emotional and cognitive difficulties. Parents

are the first teachers of a child. Parents have a contribution to the various stages of mental development or the personality of the child. In the family environment, children are at an early stage of development, could be guided and directed, and it has an effect on children future developments (Davita, Narmada & Sudjana, 2014). When parents had low self-esteem, ashamed or abandoned their children, then there is a possibility that the children would experience personality disorders. Research conducted by Murray (2008) mentioned that mothers with babies who have cleft lip showed an adverse outcomes in terms of child development, this might be due to the less response at the beginning of interactions between mother and child that interfered development of the child (Speltz, et al., 1994; Murray, et al. 2008).

Children who have cleft lip and palate have negative feelings and low acceptance levels from their parents, whereas parents have a major role in the treatment of their children (Noor & Musa, 2007). Individuals with positive self-esteem always accept themselves as they are, not blaming themselves easily for being imperfect, always feel proud and satisfied with his work and have confidence in facing life's challenges (Santrock, in Desmita, 2010). Self-esteem helps a positive relationship with the mother in educating a child during development. Parents who have high self-esteem, will be able to instill competitiveness and leadership in children (Edmondson, 2006).

Kartono (2008) stated self-esteem in women emerged after the newborn was born but the new-born was out of the expectations of her partner. A mother tends to feel the self-esteem decreases when the newborn did not match the expectations of her partner (disabled child). Reinforced by Telford and Sawret (2008), Hockenberry and Wilson (2013), and Davita, Narmada and Sudjana (2014) stated that low self-esteem in the parent was related to having children with disabilities or abnormalities.

The results also showed that a mother tends to feel a declining self-esteem when having children with disabilities or abnormalities (Hockenberry & Wilson, 2013). The study results showed that there was a relationship between feelings of shame with one's self

esteem (Dsouza et al., 2001). This showed that the embarrassment experienced by parents causes a declining self-esteem. The parents shamed experience could be seen from their behavior such as enrolling and leaving the child in the shelter, hiding the child at home, denying the presence of her disabled child, and not recognizing her child to another person (Nugroho, 2004).

The Family-Centered Care (FCC) approach in the concept of pre-school child hospitalization, families had a large involvement during the treatment, and the decision makers between patients and health care providers (Kusumaningrum, 2010). Nurses had a role as an educator in parents who had children with cleft lip and palate who experienced a change in self-esteem. Nurses provide education on how to care for children with clefts, and treatments that could be done to improve the condition of the child's lips. Nurses provide emotional support and enthusiasm to participate in making decisions whenever possible (Bruner & Suddarth, 2001). Nurses perform good therapeutic communication to foster good relationships with patients and families (Maria Iliana et al., 2010). It was expected that with the right support and information the parents' self-esteem could increase and for parents who have high self-esteem can be maintained.

YPPCBL Foundation is a foundation that helps the treatment of children Cleft Lip and Palate, and a shelter for parents who came from out of town and did not have relatives in Bandung. This foundation is located in Bandung, West Java. Patients who treated at YPPCBL came from several regions in Indonesia. By 2016, 216 children with cleft lip and palate had registered for treatment at YPPCBL, but only 198 children had surgery. Within a month about 25 children signed up for treatment, and about 15 children performed surgery on YPPCBL.

The results of interviews with YPPCBL management revealed that there were often cases of embarrassed mothers when they found out that their child had a cleft lip with / without a palate for the first time after giving birth. The mother felt embarrassed, blamed herself, upset, and did not want to breastfeed. Another case, there were some parents who

abandoned their children, left their siblings, and did not take their children to seek treatment.

Some parents said they felt embarrassed, shocked, rejected the circumstances, hid their children in the house, and did not want to socialize with the neighbors. It affected the psychological mother and child and the child's growth. Some other parents said they did not feel ashamed, just felt sorry for the condition of their children, they must rise up and seek the best treatment for their children. Some parents who knew the condition of their children since they were in the womb, so they were better prepared psychologically, looked for information about cleft lip and palate, and treatment.

According to the results of interviews with YPPCBL's management it was revealed that parents' awareness for the treatment of their children was influenced by doctors, health workers, foundations, families, neighborhoods, and the level of education and knowledge of parents. When researchers interviewed some parents about their service and feelings after following YPPCBL treatment, parents said they felt greatly helped by the foundation, and the burden diminished when they saw his son laughing happily with his friends and beginning to speak clearly. Excellent communication between YPPCBL and parents was helpful in addressing issues related to the development and healing of their children. The purpose of this study was to identify the self-esteem of parents who had children with cleft lip and palate.

Research Method

This research was a quantitative descriptive study. The study population was the parents of children with cleft lip and palate at YPPCBL Bandung. A total of 30 respondents participated in the study. Respondents were selected using the total sampling technique. Variables in this study were the self-esteem of parents of children with cleft lip and palate. Data were collected using a questionnaire consisting of two parts. Part I was the question of parent demographic data. Part II was demographic data of children, and questions about self-esteem. The research

instrument was developed based on the self-esteem dimension according to Coopersmith (1967). There were 4 dimensions, namely, significance, power, competence and virtue. Parenting self esteem instrument has been performed a content validity, construct validity ($r = 0.977$), and face validity. Cronbach's instrument reliability value $\alpha = 0.989$. The collected data was then analyzed by descriptive frequency. The results categorize high self-esteem if the score ≥ 13 and low self-esteem if the score < 13

Research Results

Table 1 shows that almost all respondents (90%) were female. Most of the respondents (73.3%) were early adults aged 21–40 years ($n = 22$). Relationships with children, most of the respondents (76.7%) were mothers ($n = 23$). Almost all respondents 83.3%, ($n = 25$) were Sundanese. All respondents who came from married status (100%). The last education for a small group (36.7%) was a junior high school graduate ($n = 11$). Most occupation were housewives, as many as 25 people.

Table 2 shows that the majority of children were treated at the age of 0–2 years ($N = 24$). 40% was the 2nd child. 63.3% were a boy (n

Table 1 Characteristic of Parents (n=30)

| Characteristic | f | % |
|--------------------|----|------|
| Gender | | |
| Male | 3 | 10.0 |
| Female | 27 | 90.0 |
| Age | | |
| Adult (21-40) | 22 | 73.3 |
| Middle (41-60) | 8 | 26.7 |
| Elderly (>60) | 0 | 0 |
| Relation | | |
| Father | 4 | 13.3 |
| Mother | 23 | 76.6 |
| Others | 3 | 10.0 |
| Ethnic | | |
| Sundanese | 25 | 83.3 |
| Javanese | 5 | 16.7 |
| Marital Status | | |
| Married | 30 | 100 |
| Education | | |
| Elementary School | 7 | 23.3 |
| Junior School | 11 | 36.7 |
| Senior School | 10 | 33.3 |
| College/University | 2 | 6.7 |
| Occupation | | |
| Employment | 1 | 3.3 |
| Housewife | 25 | 25 |
| Entrepreneur | 4 | 13.3 |

Table 2 Characteristic of Children (n=30)

| Characteristic | f | % |
|-----------------------|----|------|
| Age | | |
| Baby (0–5 tahun) | 26 | 86.6 |
| Kid (6–12 tahun) | 2 | 6.7 |
| Teenage (13–15 tahun) | 2 | 6.7 |
| Child | | |
| First | 11 | 36.7 |
| Second | 12 | 40.0 |
| Third | 3 | 10.0 |
| Fourth | 4 | 13.3 |
| Number of Children | | |
| 1 | 8 | 26.7 |
| 2 | 14 | 46.7 |
| 3 | 4 | 13.3 |
| 4 | 4 | 13.3 |
| Gender | | |
| Male | 19 | 63.3 |
| Female | 11 | 36.7 |
| Surgery | | |
| Not Yet | 4 | 13.3 |
| Yes | 26 | 86.7 |
| First Treatment | | |
| Not yet | 4 | 13.3 |
| 0–2 year | 24 | 80.0 |
| 3–5 year | 1 | 3.3 |
| 9–11 year | 1 | 3.3 |
| On going treatment | | |
| Not yet | 4 | 13.3 |
| Lip surgery | 17 | 56.7 |
| Palate surgery | 4 | 13.3 |
| Nose surgery | 1 | 3.3 |
| Dent surgery | 2 | 6.7 |
| Speech therapy | 2 | 6.7 |
| Cleft | | |
| Lip | 5 | 16.7 |
| Palate | 3 | 10.0 |
| Lip and Palate | 22 | 73.3 |
| Cleft Position | | |
| One Side | 21 | 70.0 |
| Two Side | 9 | 30.0 |

Table 3 Self-Esteem of Parents (n=30)

| Self-Esteem | f | % |
|-------------|----|------|
| Low | 12 | 40.0 |
| High | 18 | 60.0 |

Table 4 Overview of Low Self-Esteem in Parents (n=30).

| Dimention | Statement | F | (%) |
|-----------|--|----|-----|
| Virtue | I locked up my child who had a cleft lip inside the house. | 30 | 100 |

= 19). Almost all children who came to the foundation have been in operation (86.7%). Early child age at operation 0–2 years (n = 24). The current treatment was 56.7% lip surgery (n = 17). Almost all children had a cleft lip and palate 22 children or 73.7%.

Table 4 describes the feelings of parents' self-esteem especially shown from some of their behaviors

Discussion

The study found that the majority of the respondents had high self-esteem, it means most parents of children with cleft lip and palate at YPPCBL Bandung in terms of quality, behavior, and attitude had a positive self-esteem. It showed that a person accepted themselves and their situation, adjusted, looked at themselves positively, and shown strength within (Andini, 2013). Respondents with high self-esteem acknowledged that they received high care, affection, attention, and expression of love from his environment. This in line by Coopersmith's (1967) opinion that concern, attention and love of self arise because the person obtained the love and attention of the family or the nearest person. So, it can be stated that the person would have a positive assessment or self-esteem.

A small percentage of respondents had a low self-esteem. They recognized a lack of recognition, respect from others, and lack of virtue (lessons and examples of good behaviour), which referred to ethical, moral, and religious standards. A person who was compliant with the values of ethics, morals, and religion was considered having a positive attitude and behaviour and would give a positive assessment of themselves. It means that a person had developed a positive self-esteem (Coopersmith, 1967).

According to (Stuart, 1998), several factors affecting self-esteem were gender, age, education level, ethnicity, family parenting, structural and functional changes, self-responsibility failures, unreached goals, and rejection. By knowing the factors that affect the parents' self-esteem, it is expected to maintain the parents' high self-esteem, especially for parents who have children with cleft lip and palate. Self-esteem will greatly affect the psychic parents and children that will ultimately affect the child's development and treatment.

Based on the study results all respondents were female, it was related to several factors that affect the characteristics of self-esteem among the gender. According to Bosacki (1997) female have higher self-esteem than male (Bosacki, 1997). In the demographics data, the respondents were in the early adult category (26–35 years), this indicated that the older the person's age the better of the knowledge. This in line with Budiman's study that the more a person age then the more developed their mindset and understanding so it affected knowledge increase (Budiman & Riyanto, 2013).

The results showed that most of the parents who came to accompany their children for treatment were mothers (76.7%), this might due the very intimate relationship between mother and child, because in general a child spent more time with their mother since a baby. This was different from Parsons et al.'s (2011) study which reported that mothers who had children with cleft lip and palate would be less responsive, than when having children with normal faces. It would affect the parents' self-esteem and children's self-esteem.

In this study, the formal education level of respondents was diverse. The high level of one's education was directly proportional to

the complex of one's thinking insight so that one would be better able to develop himself (Rathus & Nevid, 1983). The statement implied that if the level of education is higher then the expected self-esteem is also higher

The surgery status of children also affects the level of self-esteem of parents, in this study results that almost all respondents had been in a surgery so the possibility of parents' self-esteem was high due to the improvement of the the lips of children. The initial age of the child in surgery in this study was when children aged 0–5 years. This increased the parents' self-esteem because the child had performed surgery since childhood. It could be stated that most parents already had the awareness to treat the problem of cleft lip and palate from an early age. According to research conducted by Nelson (2000), the surgery of cleft lip and palate should be done as early as possible by referring to the rule of tens, ie minimum weight 10 pounds, age 10 weeks, minimal Hb 10 gr/dl and leukocytes below 10,000 .

From 30 children who had cleft lip, most of the abnormalities were cleft lip and palate. This in line with a research conducted at Faculty of the Medicine University of Tartu, Estonia in 2012 which found more cases of cleft lip accompanied by palatum than cleft lip without palatum. There were more cases of a unilateral cleft lip than bilateral lips. Found 21 cases (70%) unilateral and 9 cases (30%) bilateral, and most often found on the left side. This was similar to the results of research conducted by Teuku Ahmad at the Faculty of Medicine, the University of Indonesia in 2012 which stated that the localization of lip cleft is more commonly found. This was because the left side development is slower than the right side.

YPPCBL Bandung stated that parents who had children with cleft lip and palate had a physical and financial burden. However, based on research results found that YPPCBL Bandung provided support in terms of psychological, financial and provided lodging for those originating from outside Bandung and have no relatives in Bandung. It gave a positive effect on the psychological parent, so this study obtained almost most parents have high self-esteem.

As a professional health worker, nurses are

expected to provide education and counseling to parents, families and related parties who have children with cleft lip and palate, not to feel ashamed of the child's condition. Nurses would advocate by introducing low self-esteem parents to high self-esteem parents, and have successfully provided care to their children. Nurses would optimize the role of peer support in providing support for parents. Parents are expected to express their feelings, appreciate the child and themselves, and demonstrate adaptive behavior in living his or her role as the child's primary caregiver. The nurse can also provide education related to illness, treatment, parenting, how to care for postoperative wounds in children with cleft lip and palate. Good cooperation between nurses and parents is expected to improve the success of child care with cleft lip, so that the quality of life of children would better.

Conclusion

The majority of parents who had children with cleft lip and palate had a high level of self-esteem. Parents had shown concern, attention, and expression of love in children. Achieving the child performance as the demands and expectations. Less than a half of parents have low self-esteem levels, it might be that parents are less likely to receive recognition and respect from others, and lack of moral, ethical and religious values.

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