

Quality of Life of Cleft Lip and/or Palate Patients' Caregivers in Jeddah

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Abstract

Aim: This study was performed to: 1) Assess the experience of the caregivers having a child with cleft lip and/or palate. 2) Determine the most important aspects affected by having such a child. 3) Find if there are any difficulties in reaching the health care providers to help such patients and families in the city of Jeddah.

Method: A telephone-administered questionnaire was collected from 42 caregivers of Cleft lip and/or palate patients who attended maxillofacial surgery clinics at King Abdul Aziz University Hospital-Jeddah.

Findings: Only 3 (7.1%) participants knew about their child's condition at the ultrasound session but none of them had enough counseling about the condition. However, 71.4% of the participants had counseling after the birth of the child. Caregivers mostly found difficulties in reaching Maxillofacial Surgery, Speech therapist, Plastic surgery, and Orthodontics. According to the caregivers' response, they reported that those children were mostly affected psychologically and physically. Nearly half of the caregivers found difficulty managing their household sufficiently. In addition, 50% of the participants were depressed before starting the treatment but only 11.9% of them remained the same after treatment.

Conclusion: This study found that counseling to the caregiver after birth of a child with cleft lip and/or palate will help the caregiver accepting this condition. Caring of such child will affect the caregiver in managing the household sufficiently and financially, however it did not affect them socially. Half of the caregivers felt depressed before the treatment of their child but the percentage dropped after treatment, and their depression did not affect their care for the child.

Keywords: Caregiver, Cleft Lip, Cleft Palate, Parents, Quality of life

Introduction

Cleft lip and/or palate is the most common congenital defect worldwide which arises in about 1.7 per 1000 live births [1]. This defect can affect the child's most basic requirement of a normal living [2] and that will eventually have an impact on the caregivers' social life, contribution to the society, and caring for the rest of the family members [3].

Type of cleft depends on the time where cleft was developed. Upper lip, nose and palate forms in two developmental phases, primary palate and secondary Palate. Primary Palate, which consists from the lip, alveolar arch, and palate that is anterior to the incisive foramen (premaxilla) occurs throughout the second month of gestation. While during the third month of gestation the secondary palate develops, which consist from soft and hard palate posterior to incisive foramen [4]. The palate forms from the fusion of the palatine shelves of the maxillary process. Palatine shelves are present vertically on each sides of the tongue, when the tongue descends due to mandible growth the palatine shelves reorient horizontally to fuse in the middle. Lack of fusion will result in cleft palate [5,6]. Cleft lip occurs when the maxillary process and medial nasal process failed to merge together.

The etiology of this defect is multifactorial. Genetic, environmental, and interaction with teratogens in early pregnancy all can lead to alterations in embryogenesis. Previous studies have identified a number of risk factors, including alcohol, tobacco [7], stress [8], obesity [9], low zinc concentrations, improper folic acid intake [10] and fever during pregnancy [11].

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Treating a child with such defect needs a multi-stage rehabilitation with a team of variable specialists including oral-maxillofacial surgeon, otolaryngologist, orthodontist, prosthodontist, speech therapist, and psychiatrist [6]. Although the psychological care is provided to the child, a healthy familial environment is essential to overcome his problems. Accordingly, the psychological well-being of the parents must be assessed [12].

Many studies in the literature focused on the surgical and the physical rehabilitation part in the treatment of cleft lip and palate patients, but only few studies have addressed the psychological aspect of both patients and most importantly their parents who are in this journey with their children since birth.

Thus the purpose of this study was to:

- 1) Assess the experience of the parents/caregivers having a child with cleft lip and/or palate.
- 2) Determine the most important aspects in their lives affected by having such a child.
- 3) Find if there were any difficulties in reaching the health care providers to help such patients and families in the city of Jeddah.

Materials and Methods

Cross-sectional descriptive study of random sample collected from oral and maxillofacial surgery clinics' records of cleft lip and/or palate patients who were treated at King Abdul Aziz University Hospital from year 2004 to 2013. The records included 94 cleft patients, only 42 patients were contacted with their caregivers and took part in our study.

A new questionnaire was designed and used in this study. It consists of 20 questions prepared in both Arabic and English, and it was answered by one caregiver for each patient. Out of 42 caregivers who were included in the study, only two were not the patient's parents (uncle and grandmother). 71% of the caregivers were females and 29% males with a mean age range of 41-50 years. The questionnaire covered the information on demographic characteristics (age, gender, occupation) for both patients and their caregivers, factors related to their condition (timing of diagnosis, stages of treatment), and the quality of the provided service. It also assessed the impact of having such a child in the different aspects of caregivers' lives.

The study was analyzed using IBM SPSS version 22. A simple descriptive statistics was used to define the characteristics of the study variables through a form of counts and percentages for the categorical variables.

Results

Our study found that only 7.1% of the caregivers knew about their child's condition at the ultrasound sound session but none of them had enough counseling about the condition before the birth of the child (Figure 1). After birth, 71.4% of the whole participants received counseling about the condition and 93% of participants who had counseling said it made them feel better (Figure 2). 43% of the parents did not accept their child at birth however 94% of them took less than a year to overcome that (Table 1). According to the treatment of the child, caregivers mostly found difficulties

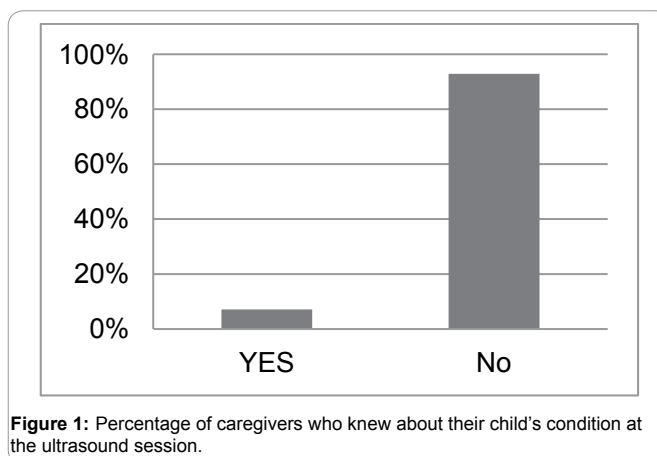


Figure 1: Percentage of caregivers who knew about their child's condition at the ultrasound session.

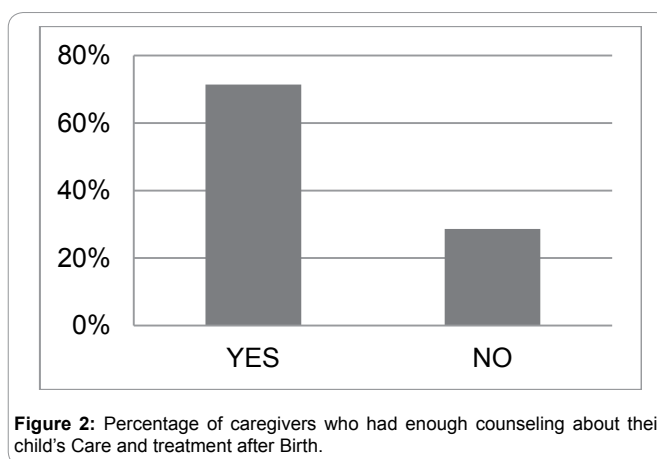


Figure 2: Percentage of caregivers who had enough counseling about their child's Care and treatment after Birth.

	Frequency	Out of	Percent
At the time of birth, did you accept your child the first time you saw him/her?(NO)	18	42	42.9
How long did it take you to accept your child's condition? (less than a year)	17	18	94.4
Did you have enough counseling about your child's care and treatments (Yes after birth)?	30	42	71.4
Did the counseling made you feel better (Yes)?	28	30	93.3

Table 1:Percentage of caregivers.

in reaching Maxillofacial Surgery followed by Speech therapy then Plastic surgery then and Orthodontics (Figure 3).

When the caregivers were asked to rate their children to normal, they reported that those children were mostly affected psychologically and physically equally, then socially and lastly in their education attainability.

Nearly half of the caregivers found difficulty managing their household sufficiently and 81% of the caregivers reported that having this child did not affect their relationship with relatives or friends, but 50% stated that having this child affected them financially. Finally, 50% of the caregivers were depressed before starting the treatment but only 11.9% remained the same after treatment (Figure 4). However, the majority of the caregivers said that their depression did not affect the care of the child.

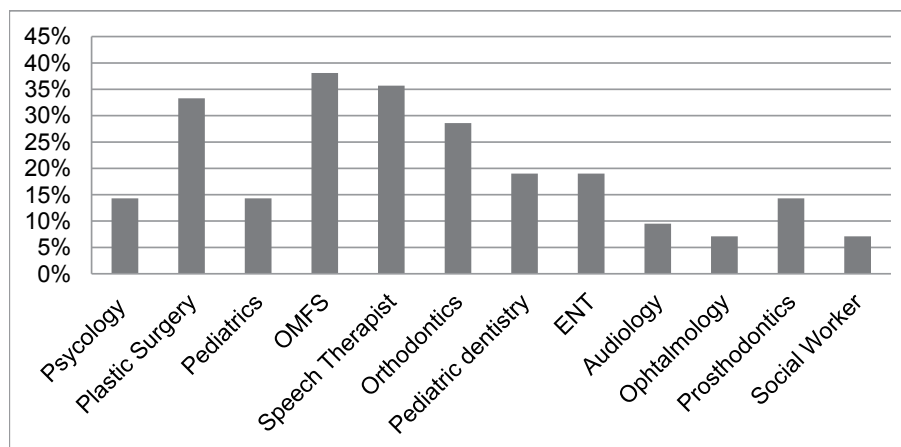


Figure 3: Difficulty in approaching medical services.

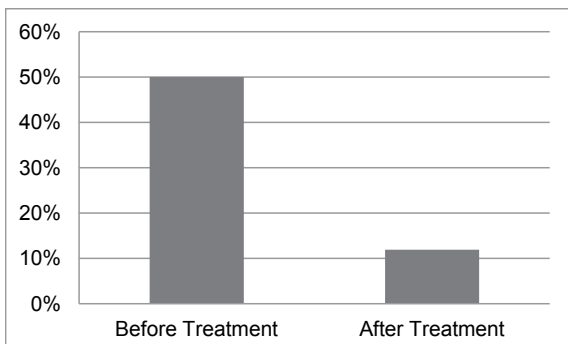


Figure 4. Percentage of caregivers who felt depressed before and after treatment of their child.

Discussion

There are many problems and challenges facing the cleft lip and/or palate caregivers. It started by having a child who does not meet their expectations as well as their constant worrying about him not being accepted socially or to be distinguished from his peers [12]. Furthermore, the cost and time consumed going through the treatment needed might develop an emotional disorder such as depression and anxiety for the caregivers [13]. This will lead to a compromise in different aspects of their lives, career, contribution to the society, and caring for the rest of the family [12].

Data collection of this study was done using old record of the hospital because we wanted to interview patients who completed treatment to see the effect of treatment on the family. Gathering them was difficult because most of them came from different cities in Saudi Arabia, so telephone questionnaire was more convenient for their contribution. 94 cleft patients phone numbers were collected from the records, only 42 patients were contacted. The rest were either wrong numbers or disconnected lines. Parents were our main target for the study however we found that an uncle and a grandmother were the main caregivers for 2 of our patients, so the subject was changed from parents to caregivers.

Maternal depression was found to effect the child development

negatively. However in this study caregivers reported that their depression had no effect on the care of the child.

Birth of a cleft child is emotionally upsetting for the caregivers of the child. In our study only 3 caregivers out of 42 were informed about their child condition. The reason for this gap should be addressed; Antenatal diagnosis is found to be psychologically beneficial. Davalbhakt and Hall 2000 study found that 85% (n=25) of those who had an antenatal diagnosis felt that the diagnosis prepared them psychologically for the birth of the cleft child [14]. On the other hand Robbins 2010 reported that Timing of the cleft diagnosis did not alter maternal satisfaction with information [15].

Many studies done in USA have investigated the depression and anxiety levels in the parents caring for children with clefts. Pope, et al. 2005 conducted a study on 47 parents and found that these parents are experiencing more emotional strains [16]. On the other hand, other studies such as Berger and Dalton 2009 [17], have suggested in their study that is conducted on 143 parents that anxiety levels are equal to those parents of children without clefts especially by the pre-school years.

However, no previous studies have investigated the psychological status of the parents in relation to their child's treatment pathway [18].

In our study, we tracked the depression of the caregivers and the treatment of their child and we found that the changing in their child's situation after treatment helped in improving their depression.

Most of the caregivers in our study had difficulties in reaching some medical specialties which in turn had an impact on their satisfaction toward the provided service.

Generally, the differences in our findings and the studies mentioned above may be attributed to the lack of longitudinal data, diverse samples or study instrument, and other cultural factors.

Finally we recommend that further studies on larger samples are suggested to explore more aspects in cleft lip and/or palate caregivers' population, systemic review shows there were no enough researches done so far, completely examining

the parents' perspective in depth [18]. Parents' education and awareness about their child's condition should be raised up and lastly, difficulties in approaching medical specialties should be addressed.

Conclusion

This study found that counseling to the caregiver after birth of a child with cleft lip and/or palate will help the caregiver accepting this condition. Caring of such child will affect the caregiver in managing the household sufficiently and financially, however it did not affect them socially. Half of the caregivers felt depressed before the treatment of their child but the percentage dropped after treatment, and their depression did not affect their care for the child.

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