



## A Comparative Study of Quality of Life of Mothers with Infants Born with Cleft Lip and Palate versus Controls Using SF-36 Health Survey

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### Abstract

**Objective:** This study aimed to compare the quality of life of mothers with children born with cleft lip and palate versus mothers with normal children.

**Methods & Materials:** In this cross-sectional study (descriptive-analytical), 23 mothers of 1 to 3 months old infants with non-syndromic unilateral cleft lip and palate as well as 23 mothers of normal, non-cleft infants as control group were assessed through the standard quality of life SF-36 questionnaire. Data were collected and analyzed using SPSS software (version 16).

Descriptive statistical analysis (mean, percentage, and standard deviation) and analytical statistical test (independent t-test) were used. (P-value <0.05 was considered as significant.)

**Results:** Present study showed the average quality of life score of mothers of infants with non-syndromic unilateral cleft lip and palate was 64.49. Also, the average quality of life score in the control group was 67.06. The mean quality of life of the two groups did not have any statistically significant differences (P=0.597).

Also, there was no significant difference between the mothers of affected infants and the control group in eight scopes of the questionnaire including general health, physical function, limitation of role play due to physical reasons, limitation of role play for emotional reasons, social function, physical pain, fatigue or cheerfulness, and mental health (P>0.05). Moreover, both groups had a weak level in terms of role limitation due to physical reasons.

**Conclusion:** According to the results of the present study, both groups did not show a high level of quality of life. Awareness of this issue can guide to providing the necessary social support for all mothers with newborn infants, especially mothers of infants with congenital anomalies such as cleft lip and palate.

**Keywords:** Cleft lip and palate, Quality of life, Infants, Parents

### Background

Cleft lip and palate is one of the most common congenital defects in the head and face area. The occurrence of a gap in the baby also causes a great shock to the parents of the affected baby, and the most appropriate way to deal with the parents is to inform and reassure them. The problems in the treatment of these patients are unique. The management of cleft lip and palate is multidisciplinary, involving both surgical and non-surgical specialties (1, 2).

Surgical reconstruction of cleft lip and palate is a common procedure carried out by oral and maxillofacial surgeons and involves the repair of the lip when the child is around 3 months of age and the primary palate any time between 6-14 months of age (2, 3).

Cleft lip and palate might affect family functioning and probably reduce the quality of life in school-age children and their parents (4). The affected children might have to

tolerate psychosocial disadvantages due to their altered speech and facial appearance, probably affecting their quality of life and family functioning (4). Kramer et al. reported that the occurrence of cleft lip and palate is a source of considerable shock to the parents of an affected baby (4). Cleft lip and palate is reported not to be a major cause of mortality in developed countries; however, it may cause considerable morbidity to affected children and imposes a substantial financial risk for families, with a concomitant societal burden (4). Thus, this study was designed to compare the quality of life of mothers of cleft lip and palate infants versus mothers with healthy infants.

## Methods

This case-control study was based on data obtained from 23 mothers of non-syndromic unilateral cleft lip and palate infants referred to Cleft Lip and Palate Clinic of Akbar Children Hospital, Mashhad, Iran as well as infants referred to Health Monitoring Center during one year period (from June 1, 2020, to June 31, 2021). All patients were residents of Khorasan province in Iran, an area of approximately 124,432 km<sup>2</sup> around the town of Mashhad. Most of the patients have been referred to in the early days after birth from various hospitals or other physicians.

Inclusion criteria consisted of married mothers living with their spouse, having an infant with unilateral non-syndromic cleft lip and palate, being literate, and having maximum of one child with cleft lip and palate. All affected infants were examined by a pediatrician and a medical geneticist to diagnose medical problems and to distinguish syndromic cases from others. The age of the samples was between 1 to 3 months after birth. Exclusion criteria consisted of having another child under one year, having an infant with syndromic cleft lip and palate, having an infant with bilateral cleft lip and palate, having an infant under one month and over three months, and presence of proven mental illness in the mother. In this study, the study objectives were first explained to the mothers, and their consent to participate in the study was obtained.

The SF-36 Health Survey is a generic instrument for the assessment of the health-related quality of life of patients. The SF-36 assesses 8 subscales of the health-related quality of life, or subjective health, which are

conceptually subsumed in the areas of "physical" and "mental" health.

The Persian version of the SF-36 quality of life questionnaire was used in this study (5, 6). The SF-36 is a well-recognized, self-administered quality of life scoring system. The purpose of this questionnaire is to assess the state of health in terms of both physical and mental conditions. It contains 36 questions measuring health across eight different dimensions - physical functioning (PF), role limitation because of physical problems (RP), social functioning (SF), vitality (VT), bodily pain (BP), mental health (MH), role limitation because of emotional problems (RE) and general health (GH).

To calculate the score of the questionnaire, based on the score key that is available in the interpretation of the questionnaire, each answer to the questions was scored. And the answers were rated between zero and one hundred (A value of 100 was assigned to different answers in different questions. Thus, in questions number 1, 2, 20, 21, 22, 23, 26, 27, 30, 34, 36 option 1, in questions number 3 to 12 option 3, in questions number 13 to 19 option 2, in questions number 24, 25, 28, 29 and 31 option 6 and in questions number 32, 33 and 35 option 5 scored 100 points).

Then we added the score of the expressions of each domain and calculated the average of each domain ( Each area contained several questions, which are arranged in this order: Question 1 and questions 33 to 36 were in the field of general health, questions 3 to 12 were in the field of physical function, questions 13 to 16 were in the field of limitation of role-playing for physical reasons, questions 17 to 19 were in the field of limitation of role-playing for emotional reasons, questions 20 and 32 were in the area of social functioning, questions 21 and 22 were in the area of physical pain, questions 23, 27, 29, 31 were in the area of fatigue or vitality, and questions 24, 25, 26, 28 and 30 were in the area of mental health). To calculate the total score of the questionnaire, the sum of the numbers obtained from each subscale was divided by 8. Finally, the obtained scores were between 0 and 100. The closeness of the score to 100 was a sign of a better level of quality of life.

All data were analyzed using SPSS software version 16 (IBM, Armonak, NY, USA). An independent t-test was used to compare the variables between the two groups. P-value <0.05 was considered as significant.

## Results

The mean age of samples was 26.8±5.3 years in the case group and 31.04±6.3 years in the control group and according to the independent T-test, there was a significant difference between the two groups in this regard (P-value=0.02).

Although the relationship between the age of mothers and quality of life was linear, there

was no significant correlation between them, so age was not a confounding factor and cannot affect the final results of this study (N=46, P=0.274, rp=0.165).

According to Table 1, in general, there were no significant differences in the quality of life of mothers with infants born with cleft lip and palate and mothers with normal infants (P=0.59).

**Table 1.** Comparative evaluation of the quality of life means and standard deviations in case and control groups

Group	Number	Mean ± SD	Median	Max-Min	Independent T-test
Case	23	64.49±16.12	61.94	100-41.53	T=0.53
Control	23	67.06±16.62	68.61	93.47-36.11	P=0.59

**Table 2.** Comparative evaluation of the quality of life means and standard deviations in case and control groups in 8 subscales

SF-36 subscales	Group	Number	Mean ± SD	Median	Maximum Minimum	Independent t-test results
General health	Case	23	66.95±21.78	75	100-15	T=1.18
	Control	23	73.26±13.19	75	95-40	P=0.24
Physical functioning	Case	23	73.34±23.36	85	100-25	Z=45.26
	Control	23	73.14±22.29	80	100-25	P=0.9
Role- physical	Case	23	40.21±39.69	25	100-0	Z=43.86
	Control	23	42.50±44.12	25	100-0	P=0.96
Role -emotional	Case	23	53.62±41.11	66.66	100-0	Z=42.33
	Control	23	66.66±46.05	100	100-0	P=0.25
Social functioning	Case	23	82.06±72.57	75	100-25	Z=44.82
	Control	23	68.47±27.14	75	100-0	P=0.92
Vitality	Case	23	62.39±17.82	60	100-30	T=0.234
	Control	23	63.69±19.95	65	100-20	P=0.81
Mental health	Case	23	69.39±18.70	72	100-72	Z=45.28
	Control	23	72.18±17.94	76	96-76	P=0.52
Bodily pain	Case	23	52.82±25.45	45	100-10	Z=45.19
	Control	23	67.06±24.89	77.5	90-10	P=0.06

Table 2 shows there was no significant difference between mothers of infants with cleft lip and palate and the control group in 8 questionnaire subscales (p>0.05).

### Discussion

Babies born with cleft lip and palate have many physical and functional problems and they have to go through a long and complicated treatment period, also this congenital anomaly affects their families (7).

According to the results of this study, the mean quality of life score was 64.49 in the case group and 67.06 in the control group. Quality of life scores in both groups are not at a good level compared to the highest score of the questionnaire (100); therefore, it can be concluded that the quality of life is affected in both groups.

In addition, in all subscales of quality of life, including general health, physical function, role limitation for physical reasons, role limitation for emotional reasons, social function, physical pain, fatigue or vitality, and mental health no significant differences were

found between the two groups. The scores of both groups in "role limitation for physical reasons" were lower than other subscales that need more attention.

Also, in the field of "social functioning", the case group score was higher than the control group. It may be due to social relationships with other professionals and the support of their families.

Most psychosocial researches have been focused on the effect of the condition on the affected person, and the effect of this congenital anomaly on a person's family has received less attention (8). However, some of these studies have shown that cleft lip and palate do not have a significant effect on mental health status and consequently on parents' quality of life. (8, 9, 10) Baker et al. reported that despite the effects of cleft lip and palate on affected children, negative consequences and parents' level of psychosis were not high and parents had a high level of positive adjustment to their child's abnormal condition.(8)

Berger et al. also found that mothers of adolescents with cleft lip and palate did not

report more psychosocial disturbances than the normal population. (9) Another interesting result was obtained in the study of Naros et al. They reported no significant differences in the quality of life of cleft lip and palate patients and the general population. They hypothesized that the special attention of parents and the support of speech therapists and other medical professionals may have contributed to the positive impact on family interaction, communication skills, and self-esteem. (11)

Emeka et al. assessed the quality of life in families with children with cleft lip and palate before and after surgery. The results showed that 95% of mothers' quality of life was affected before surgery. (12)

In this regard, Kramer et al. found parents of children with cleft lip and palate had a lower quality of life than their children. Also, families with children with cleft lip and palate were more affected than families with children with isolated cleft palate. (13)

In the present study, mothers with children with cleft lip and palate did not have a high level of quality of life, which indicates that their quality of life is affected; but on the other hand, the quality of life of mothers with healthy babies was affected to the same extent and there was no difference between mothers with infected babies and mothers with healthy babies.

Also, there was no significant difference between the two groups in the six areas of the questionnaire. Differences were observed between the two groups in the two areas of physical pain and mental health. Mothers of infants with cleft lip and palate had more physical pain and less mental health than mothers of healthy infants. The results of research on this subject are different, some studies, such as Baker, Berger, and Schuster state that the presence of cleft lip and palate in the child has no reported effect on the mother. (8, 9, 14) Some other studies, such as Emeka, Awoyale, and Kramer show different conclusions that the presence of cleft lip and palate in the child affects the quality of life of the mother. (12, 13, 15) Overall, many studies have shown that having a child with cleft lip and palate is an unpleasant experience for the family and usually affects the quality of life of the family.

## Conclusion

According to the results of this study, there was no significant difference between the quality of life of mothers of infants with cleft

lip and palate and mothers of healthy infants. It was also found that the quality of life of both groups was affected. Based on this evidence, it can be concluded that the presence of an infant under three months (healthy and with cleft) affects the quality of life of mothers. Also, mothers of affected infants have more physical pain and less mental health than mothers of healthy infants.

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