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치의학석사 학위논문

**Comparison of caregivers' parenting
burden between cleft and non-cleft
patients in pre-adolescence and
adolescence under orthodontic treatment**

학령기 구순구개열 교정 환자와 일반 교정 환자의
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**Comparison of caregivers' parenting
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under orthodontic treatment**

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Abstract

1. BACKGROUND

Cleft lip and/or palate (CLP) is one of the most common congenital deformities in the head and neck region throughout the world. Many researchers have found that the caregivers of congenitally disordered patients have different characteristics such as depression, anxiety and parenting stress. Since CLP patients tend to have the mid-face deficiency and Class III malocclusion, they need the life-long orthodontic treatment and periodic check-ups. CLP patients in young age visit the orthodontic clinics with their caregivers, who frequently interact with dentists.

The main aim of this study was to compare the burden from parenting between caregivers of CLP and non-CLP.

2. METHODS

Subjects consisted of 80 caregivers of patients aged 8 to 15 years who visited the Department of Orthodontics at Seoul National University Dental Hospital from August 21st, 2017 to September 8th, 2017. To enhance the study reliability, only female caregivers, mothers, were selected for this research. Subjects were divided into two groups; Group A (experimental group, caregivers of patients with CLP, n = 44) and Group B (control group, caregivers of patients with non-CLP, n = 36). CLP and all types of congenital deformities were excluded for Group B.

Two types of questionnaires focusing on the level of burden and stress from parenting

were distributed to subjects; Burden Interview (BI) and Bangor Mindful Parenting Scale (BMPS). Higher total scores indicate the greater level of parenting burden for both scales.

Statistical comparison of total scores between two groups and subgroup analyses in each score were performed with a significance level of 0.05 (SPSS, Chicago, IL, USA).

3. RESULTS

1) Although the experimental group (Group A, caregivers of CLP patients) showed higher average scores for both BI and BMPS than the control group (Group B, caregivers of non-CLP patients), (Group A, Group B: BI 14.55 vs. 12.91, BMPS 18.13 vs. 17.32), there were no significant differences between Groups A and B for both BI and BMPS. (p value = 0.665 for BI and 0.448 for BMPS)

2) For Group A, five types of CLP found; cleft lip, cleft palate, unilateral cleft lip and alveolus, unilateral cleft lip and palate and bilateral cleft lip and palate. Both BI and BMPS had tendency to have higher scores with increasing severity of CLP, however, there were no significant difference among the cleft types.

3) In both Groups A and B, caregivers of female patients tend to show higher BI and BMPS scores than those of male patients, however statistical difference between patient genders was not found.

4. CONCLUSION

Although the result in this study indicated that the caregivers of CLP patients have a tendency of higher parenting burden level, the parenting burden of caregivers of CLP patients especially on the orthodontic treatment may be the same with that of non-CLP pa-

tients.

Keywords: Cleft lip and palate, Caregiver, Caregiver burden, Parenting burden,
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I. Introduction

1. Study Background

Cleft lip and/or palate (CLP), also known as orofacial cleft, is one of the most common congenital malformations occurring in the craniofacial region (Trotman et al., 1993). CLP includes cleft lip (CL), cleft palate (CP), and both together (CLP) (Watkins et al., 2014).

The etiologies of CLP are known as heredity, old age of mother, malnutrition (Wallace et al., 2011) and many others. CLP patients experience diverse problems on feeding, speech, hearing, and social integration and these problems can be corrected in a multidisciplinary approach in a combination of surgery, dental treatment, speech therapy and psychosocial intervention (Dixon et al., 2011).

Within 1 to 2 years after birth, most CLP patients undergo lip and/or palate surgery and after the investigation of initial growth pattern, orthodontic and orthopedic treatment follows (Seo et al., 2011). Patients with CLP often develop maxillary deficiency due to congenital deformities and surgical scar caused by primary surgery (Baek et al., 2002). In addition, vertical growth pattern and occlusal interference are also characterized in CLP patients (Baek et al., 2010). For successful treatment of CLP, practical skill, in-depth knowledge of abnormal anatomy, and appreciation of three-dimensional facial aesthetics

are essentially required (Thorne et al., 2007). A comprehensive management of CLP patients can be accomplished by the multidisciplinary team approach and the dentists play a crucial role in the team (Malik et al., 2012). For a long time, it has been known that the early involvement of orthodontists for CLP treatment is becoming a fact of life (Jacobson et al., 1984) for optimal treatment effect. This is because CLP patients have a variety of dental problems such as congenital missing tooth, severe crowding, rotated tooth, and most frequently, Class III malocclusion with maxillary hypoplasia (Baek et al., 2002).

Family caregivers experience a multitude of strains, due to communication, economic concerns, and emotional conflicts (Teschendorf et al., 2007). CLP is known to impose a substantial societal burden on their family caregivers (Wehby and Cassell, 2010). Researchers have found that the caregivers of CLP tend to be less accepting of their children and more anxious about their children's future (Brantley and Clifford, 1979). Furthermore, Klein et al (2006) interviewed the caregivers of children ages 9 – 14 years old with craniofacial anomalies and found out that the caregivers' responses indicated more anxiety and protectiveness.

Few studies have explored the psychological distress and parenting burden in parents or caregivers of children with CLP. Caregivers, especially mothers of children with CLP had experienced the depression, anxiety and burden on parenting (Jeong et al., 2013). It has been also reported that the elevated stress levels in mothers correlated with reduced social skills in their children (Pope et al., 1997).

2. Purpose of Research

The core objective of the present research was to compare the level of burden from parenting between caregivers of CLP patients and caregivers of non-CLP patients.

In this study, we analyzed the parenting burden level of caregivers of CLP patients in comparison with those of non-CLP patients who visited the orthodontic clinic on a regular basis, and performed sub-analyses on the parenting burden levels within cleft types and gender of patients.

II. Material and Methods

1. Participants

Eighty caregivers of 8 to 15 years old patients who visited the Department of Orthodontics at Seoul National University Dental Hospital from August 21st, 2017 to September 8th, 2017 were recruited to be the subjects of this study. To enhance the study reliability, only female caregivers, mothers were selected for this research. Compared to male caregivers, female family caregivers are known to consistently report significantly higher levels of burden, stress, anxiety and fatigue (Brazil et al., 2009).

The study population was divided into two groups; Group A (experimental group, caregivers of patients with CLP, n = 44) and Group B (control group, caregivers of patients with non-CLP, n = 36). CLP and all other types of congenital deformities were excluded for Group B. In addition, we limited the age of children to 8 – 15 years because in both Groups A and B, similar orthodontic treatment plans are conducted at this age group of patients. As **Table 1** indicates, the average age of patients was 11.84 years old and the age of the caregivers participating in this research was between 45 and 51 years old (average = 47.5, SD = 2.27).

2. Questionnaires

Two types of self-reported questionnaires were distributed to subjects; Burden Interview (BI) and Bangor Mindful Parenting Scale (BMPS). Both scales put emphasis on the burden and stress level from parenting and the higher total scores indicate the greater level of parenting burden. Even though both scales were originally in English (see **Appendix**), well-translated and cautiously reviewed Korean versions were used in this research. Since not every caregiver participated in both BI and BMPS questionnaires, the sample population of each questionnaire differs (BI and BMPS, $n = 71$ and 57 , respectively). Among numerous questionnaires developed to quantify the caregiver burden, BI was selected for this research in that BI is one of the most widely referenced scales. BMPS was additionally chosen to measure the caregivers' burden specifically from parenting.

This research was reviewed and approved by the Institutional Review Board of Seoul National University School of Dentistry (IRB number = *S - D20170022*).

2-1. Burden Interview (BI)

Burden Interview (BI) is one of the most widely referenced scales in the studies of caregiver burden (Lukhmana et al., 2015) and this scale is known as a standard and validated tool for assessment of burden on family caregivers with Cronbach's alpha, 0.92 (Zarit et al., 1980).

BI consists of 22-item focusing on the subjective responses of caregivers. The score range is 0 – 88 and the higher total score indicates the higher level of parenting burden of caregivers. This scale was originally designed for caregivers of dementia or cognitive impaired patients but currently this has been widely used for measuring the parenting and caregiver burden.

Respondents rated 22 statements as either '*never, rarely, sometimes, quite frequently or nearly always*' in 0 – 5 scales. Total BI scores were subdivided into four levels; '*little or no burden* (BI total scores 0-20)', '*mild to moderate burden* (21-40)', '*moderate to severe burden* (41-60)', and '*severe burden* (61-88). A full copy of the scale is available in the Appendix.

2-2. Bangor Mindful Parenting Scale (BMPS)

Bangor Mindful Parenting Scale is a 15-item instrument measuring the mindfulness specifically on parenting role (Jones et al., 2014). Caregivers were asked to circle the response that best describes themselves when they are parenting their child in 0 – 4 scales. (0: *never true*, 1: *sometimes true*, 2: *often true*, and 3: *always true*) This scale is a new measure developed and used for the first time by Jones et al (2014). A full copy of the scale is also available in the Appendix.

BMPS was formerly designed to investigate the parenting burden of caregivers who have child with autism, however this can easily be changed to refer to a child of interest in a research. This scale was initially based on the ‘Five Facets Mindfulness Questionnaire (FFMQ)’ which places of interest in five factors; observing, describing, acting with awareness, non-judging of inner experiences, and non-reactivity to inner experience (Baer et al., 2006). Even though with three questions each, BMPS also has such five domains, rather than sub-scale level, we used the total score of BMPS like BI analysis, as a general tendency to be mindful in the parenting context. Likewise, higher total score indicates the higher level of parenting burden.

3. Data Analysis

All statistical analyses were performed by using Statistical Package for Social Sciences (SPSS, Chicago, IL, USA) with a significance level of 0.05. To find out whether the variables have normal distribution or not, Kolmogorov-Smirnov Test of Normality was tested in advance. If the variables had a normal distribution, we conducted independent t test, and otherwise Mann-Whitney U test was selected. We analyzed the average scores of BI and BMPS and compared the differences between Groups A and B. We also performed the subgroup analyses based on the cleft type categorization and the gender of patients using independent t test as well.

III. Results

1. Burden Interview (BI)

The average score from the Burden Interview was 14.55 with standard deviation of 10.38 in Group A, the caregivers of patients with CLP. In Group B, the average BI score was 12.91 and the standard deviation was 7.54 (**Table 2**). Group A showed arithmetically higher BI average score than Group B which demonstrated that the caregivers of CLP patients had higher level of parenting burden.

To compare the average scores of Groups A and B, Mann-Whitney *U* test was conducted because BI did not show the normal distribution by Kolmogorov-Smirnov normality test. There was no statistically significant difference in BI scores between Groups A and B (p value = 0.665) (**Table 2**).

Interestingly, both groups showed quite low BI scores (**Table 3**). In Group A, except only one caregiver (2%) who showed '*moderate to severe burden*', every caregiver showed either '*little or no burden*' or '*mild to moderate burden*' of whom the majority (34 caregivers, 77%) scored '*little or no burden*'. Group B also showed almost identical BI score distribution in that only one caregiver (3%) had '*moderate to severe burden*' and 26 caregivers (72%) had '*little or no burden*'.

2. Bangor Mindful Parenting Scale (BMPS)

In Group A, the average score from Bangor Mindful Parenting Scale (BMPS) was 18.13 with standard deviation of 4.12 and in Group B, the average was 17.32 and the standard deviation was 3.72 (**Table 4**). Similar to BI, Group A showed arithmetically higher BMPS average scores than Group B as well.

To compare the average scores of Groups A and B, independent *t* test was conducted because BMPS showed the normal distribution by Kolmogorov-Smirnov normality test. There was no statistically significant difference in BMPS scores between Groups A and B (*p* value = 0.448) (**Table 4**).

3. Subgroup analyses

Tables 5 through **7** and **Figures 1** through **6** show the result of subgroup analyses of BI and BMPS scores of Group A by cleft types and the scores of Groups A and B by patient's gender.

3-1. Subgroup analysis: cleft type

The subgroups according to cleft types and severity were also analyzed because this might convey more detailed information about parenting burden and challenges that caregivers might have (Kim et al., 2015).

Both BI and BMPS were compared in five subgroups of Group A: cleft lip (CL), cleft palate (CP), unilateral cleft lip and alveolus (UCLA), unilateral cleft lip and palate (UCLP), and bilateral cleft lip and palate (BCLP). Both BI and BMPS tend to show higher scores with increasing severity of CLP, however there was no statistically significant difference among the subgroups (**Tables 5 and 6, Figures 1 and 2**).

3-2. Subgroup analysis: patient's gender

Independent *t* test result was conducted and all of *p* values were greater than 0.05, which demonstrated that there was no statistically significant difference of both scales between patient's genders. Even though in both Groups A and B, caregivers of female patients tend to show higher BI and BMPS scores than those of male patients, statistical differences were not found (Group A: **Figures 3 and 4**, Group B: **Figures 5 and 6**).

Patients in Group A were composed of 29 male patients and 15 female patients with CLP. For BI, the average score of caregivers of female patients was higher than that of caregivers of male patients (14.4 and 12.46, respectively). On the contrary, the average score of caregivers of male patients was higher than that of caregivers of female patients for BMPS (17.11 and 16.87, respectively). However, no statistical significance was found in both scales (*p* value = 0.572 for BI and 0.928 for BMPS) (**Table 7**).

For Group B, as the control group, patients consisted of 14 male patients and 22 fe-

male patients and they all had received the general orthodontic treatment. Caregivers of female orthodontic patients showed higher – or slightly higher – average scores than those of male patients for both BI and BMPS. (BI: 15.81 and 12.54, BMPS: 18.71 and 18.62, respectively) (**Table 7**).

IV. Discussion

1. Parenting burden of caregivers

In this present study, we focused on the assessment of parenting burden of caregivers of CLP patients comparing with caregivers of typically developing children under orthodontic treatment. Deeken et al (2003) defined the caregiver's burden as objective when it corresponds to the physical and/or mental effects arising from the act of caring; and as subjective when associated with the negative sensation which the act of parenting provokes in the caregiver. Disabled children may burden their parents, who are their long-term caregivers (Elmstahl et al., 1996) and these children might affect negatively on their caregiver's quality of life (Evans et al., 1993). Many studies have reported that the patients with CLP need a long-term, occasionally a life-long, and a wide range of orthodontic treatment (Hong et al., 2009).

Parenting burden is one of the central factors of quality of life and personality characteristics of caregivers. Among many instruments developed for measuring the burden of care (Deeken et al., 2003), in this study we selected BMPS and BI which implies for physical and emotional well-beings, social relationships, and awareness of burden and it refers to the time made available for the care (Sczufca, 2002).

2. Main findings and clinical implication from BI and BMPS

Total 80 female caregivers completed the questionnaires in this study and we found that the caregivers of CLP patients showed arithmetically higher level of parenting burden according to both scales; BI and BMPS, compared to caregivers of non-CLP patients (Group A and B: BI 14.55 and 12.91; BMPS 18.13 and 17.32, respectively) (**Tables 2 and 4**). However, statistical significance between groups were not found in this research (p value = 0.665 for BI and 0.448 for BMPS) (**Tables 2 and 4**). Leung and Li-Tsang (2003) demonstrated that the caregivers whose children have disabilities are often reported to have both physical and psychological stress related to their parenting. As mentioned, disabled children might influence their caregiver's quality of life in a negative way (Evans et al., 1993). Leung and Li-Tsang (2003) studied the quality of life among parents who have children with or without disabilities and demonstrated the similar results to ours. A total of 147 parents, 71 parents with disabled children and 76 parents without disabled children, were recruited by convenience sampling for quality of life measurement. They attested that, between two groups of parents, in the context of quality of life, the social relationships and environmental domains differed significantly, yet significant differences between the two groups were not found in physical and psychological domains.

Parenting burden depends on diverse features such as the types of disabilities of child or patient, the total amount of parenting time, and the level of psychological distress. It is very difficult to quantify the parenting burden and stress level accurately because the standard is not clear. Moreover, caregivers could have not considered the total level of

distress or burden from overall context of parenting but concentrated on their recent life events and circumstances in that psychological burden scales such as Burden Interview (BI) could be affected by numerous environmental factors than the real parenting burden. Moreover, in our study, the questionnaires were conducted at orthodontic clinics, and caregivers might have focused more on their burden from orthodontic treatment rather than the general parenting burden itself. Also, the orthodontic treatment plans are not different between both groups of patients in age of 8 – 15 years. If our age group of patients were older or wider than 8 – 15 years old, caregivers of CLP patients might have significantly higher level of parenting burden in that their CLP patients would be under more complex and demanding orthodontic treatment course. Moreover, the caregivers of CLP patients might have anticipated a great sense of esthetic improvement on their patients since they have better understanding of enhanced treatment approaches and developing technologies of CLP from various information sources such as Internet, which might cause low scores on both BI and BMPS as caregivers of non-CLP patients.

In addition, in the present study, we sub-analyzed the BI and BMPS scores with cleft types and patient gender (**Tables 5 through 7, Figures 1 through 6**). Our results on cleft types demonstrated that both BI and BMPS tend to show higher scores with increasing severity of CLP, however significant difference among the cleft types in both scales were not found (**Tables 5 and 6, Figures 1 and 2**). According to the studies done by Leung and Li-Tsang (2003), parents whose children have more severe disabilities were found to have lower scores in physical, psychological and environmental domains of quality of life in those children tend to be more physically dependent on their parents. Like cleft types, our

second sub-analysis on patient gender showed similar result. We found that both scales tend to show higher scores by caregivers of female orthodontic patients compared to those of male patients, again, statistical difference between patient genders was not found (**Table 7**). Many studies proved that female family caregivers report higher levels of burden and stress than male caregivers (Schrack et al., 2016), and the patient gender. In addition to the gender of caregiver, there is a prior study related to patient genders in appearance and attractiveness norms. Lewinsohn et al. (1994) found that girls have more concerns on their facial differences and their caregivers might accordingly have chance of higher parenting burden level.

As both physical and psychological well-beings of caregiver might directly influence not only their children but also their health care providers during the treatment, appropriate caregiver support would be necessary when providing intervention to their children or patients with congenital disabilities, such as CLP. Parks and Novielli (2000) mentioned that caregiver burden and stress can be reduced by active coping and management capacities because these skills are related to lower levels of caregiver burden. Numerous studies have demonstrated the various factors affecting the caregiver's burden, for example, Macedo et al (2015) reported that the socio-demographic and health variables such as education level, family income, unemployment, number of children, the incidence and the degree of signs and symptoms of depression, anxiety and strain from daily life. Nevertheless, there is another study with different result that neither caregiver's ethnicity, gender, relationship to the patient, nor patient gender significantly influence on caregiver burden or quality of life (Wicks et al., 1997).

3. Limitations and need of further studies

Several limitations existed in our study. First, our study was based on insufficient number of sample size ($n = 80$) which might cause the statistical insignificance between groups and among variables. Second, the patient age was limited to a narrow range of 8 – 15 years old. Finally, various factors and demographic information on caregivers which could affect the parenting burden were not fully obtained.

For the future study, first of all, multicenter cross-sectional study with large number of sample size would be favorable to find more statistically meaningful results. Main advantages of multicenter study are the large number of sample size for long period of time and various variables can be measured. According to the data published by Statistics Korea, the total number of livebirth in 2016 was 406,300. The incidence of CLP in South Korea is known as 1/800 (Min et al., 1996). Therefore, approximately the sample size of 508 would be ideally recommended for obtaining statistically significant and realistic results by the sample size determination statistics (Get Sample Size Program, Dental Life Science Research Institute Seoul National University Dental Hospital, Seoul, South Korea), and this could be achieved through multicenter cross-sectional study design.

Second for the future study, other than presence or severity of CLP, a variety of factors that could affect the personality and parenting burden should be gathered and studied with analysis. Many studies have shown the association of parenting burden with many socio-economic or socio-demographic factors (Siefert et al., 2008). Caregiver burden, or

parenting burden is considered as multi-dimensional reaction resulting from an imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources and many other factors (Grunfeld et al., 2004). Other factors such as patient's academic achievement level, age, and caregivers' education level, family financial incomes and diverse factors on their socio-economic positions or status should be fully surveyed and analyzed in next research.

Third, questionnaires would be conducted in a more constructive way such as using pre-paid envelopes and a full packet of questionnaires including ones that could reflect their personality characteristics in depth with research consent form in that this could promote the more reliable replies.

V. Conclusion

Caregivers of CLP patients showed no significant difference in parenting burden compared to those of non-CLP patients. The parenting burden of caregivers of CLP patients especially on the orthodontic treatment may be similar with that of non-CLP patients.

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Table 1. Demographic data for patients and caregivers

		Group A (n = 44)	Group B (n = 36)	Total (n = 80)	
Patient	Age (year)	11.51 ± 3.98	12.24 ± 2.51	11.84 ± 3.39	
	Gender	Male	29	14	43
		Female	15	22	37
Cleft type	CL	2	/	/	
	CP	10			
	UCLA	8			
	UCLP	17			
	BCLP	4			
Caregiver	Age (year)	47.33 ± 1.86	48 ± 4.24	47.5 ± 2.27	
	Gender	All Female (100%)			

*Abbreviation: CL = cleft lip; CP = cleft palate; UCLA = unilateral cleft lip and alveolus;
UCLP = unilateral cleft lip and palate; BCLP = bilateral cleft lip and palate

Table 2. Comparison of BI scores

	n (%)	BI	p value
		Mean ± SD	
Group A	38 (53.52%)	14.55 ± 10.381	0.665
Group B	33 (46.48%)	12.91 ± 7.535	
Total	71		

*Mann-Whitney *U* test was performed.

Table 3. Level distribution of BI scores

Score	Level of burden	Group A: n (%)	Group B: n (%)
0-20	Little or no burden	34 (77%)	26 (72%)
21-40	Mild to moderate burden	8 (18%)	9 (25%)
41-60	Moderate to severe burden	1 (2%)	1 (3%)
61-88	Severe burden	0 (0%)	0 (0%)
Total		43	36

Table 4. Comparison of BMPS

	n (%)	BMPS	<i>t</i>	p value
		Mean ± SD		
Group A	32(56.14%)	18.13 ± 4.117	0.764	0.448
Group B	25(43.86%)	17.32 ± 3.716		
Total	57			

*Independent *t* test was performed.

Table 5. Comparison of BI scores according to cleft types in Group A

Score	1 (CL)	2 (CP)	3 (UCLA)	4 (UCLP)	5 (BLCP)
n	1	10	8	17	4
BI average	-	13.13	13.71	14.2	14

*Abbreviation: CL = cleft lip; CP = cleft palate; UCLA = unilateral cleft lip and alveolus; UCLP = unilateral cleft lip and palate; BCLP = bilateral cleft lip and palate

Table 6. Comparison of BMPS scores according to cleft types in Group A

Score	1 (CL)	2 (CP)	3 (UCLA)	4 (UCLP)	5 (BLCP)
n	2	6	5	13	3
BMPS average	26	17.67	16.2	17.85	16

*Abbreviation: CL = cleft lip; CP = cleft palate; UCLA = unilateral cleft lip and alveolus;
UCLP = unilateral cleft lip and palate; BCLP = bilateral cleft lip and palate

Table 7. Comparison of BMPS scores according to patient's gender

		n	BI	BMPS
			Mean \pm SD	Mean \pm SD
Group A (n = 44)	Male	29	12.46 \pm 10.23	17.11 \pm 4.67
	Female	15	14.40 \pm 11.31	16.87 \pm 5.34
	<i>p</i> value		0.572	0.928
Group B (n = 36)	Male	14	12.54 \pm 8.62	18.62 \pm 4.25
	Female	22	15.81 \pm 10.89	18.71 \pm 3.98
	<i>p</i> value		0.262	0.946

FIGURES

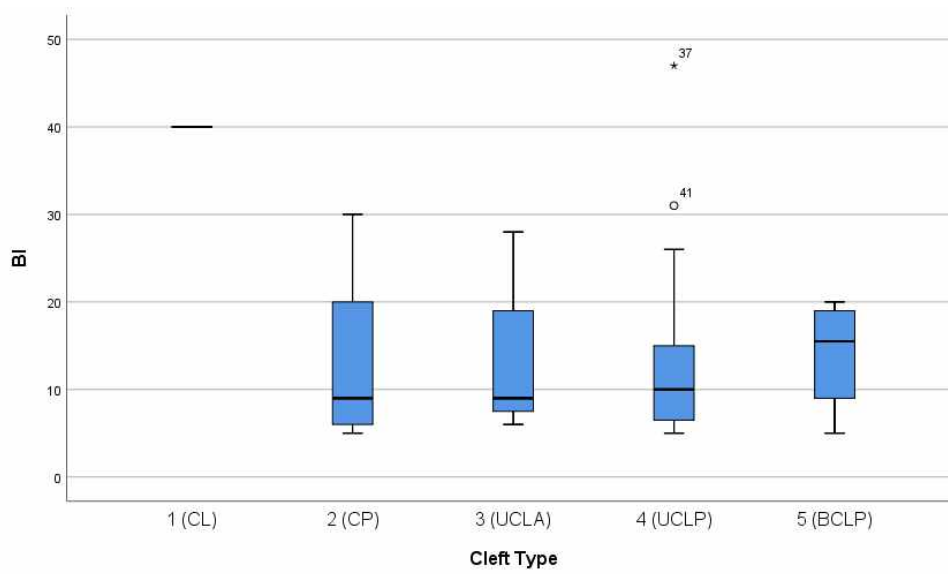


Figure 1. BI scores according to cleft types in Group A.

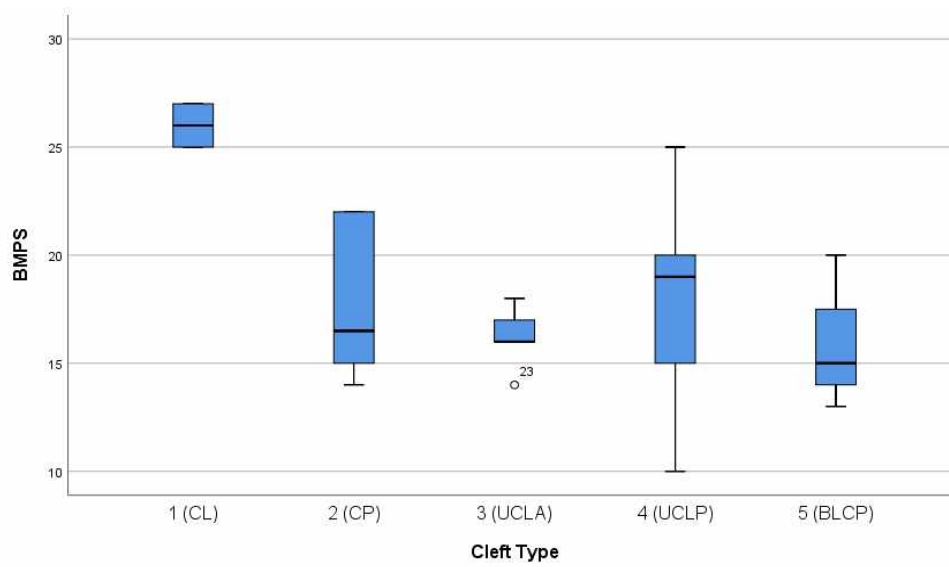


Figure 2. BMPS according to cleft types in Group A.

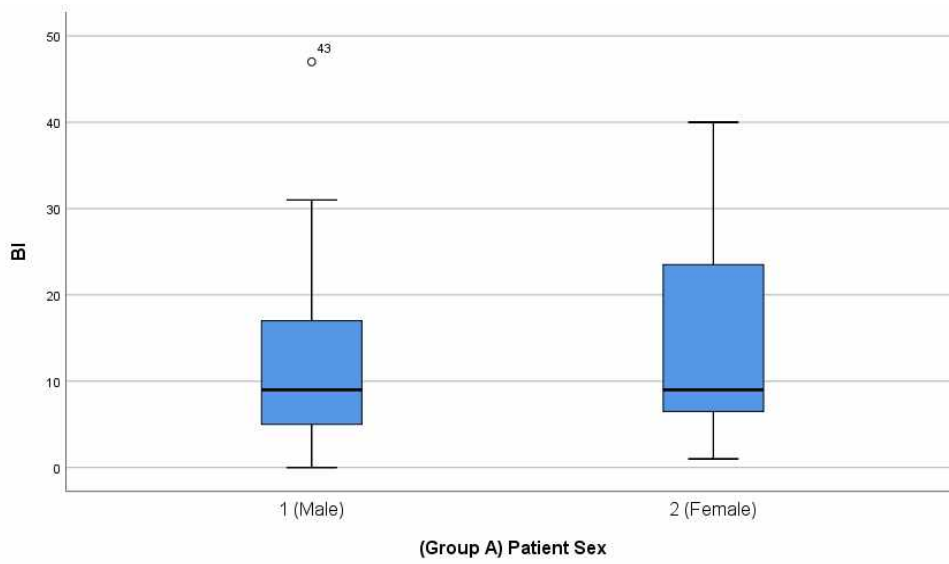


Figure 3. BI scores according to patient's gender in Group A.

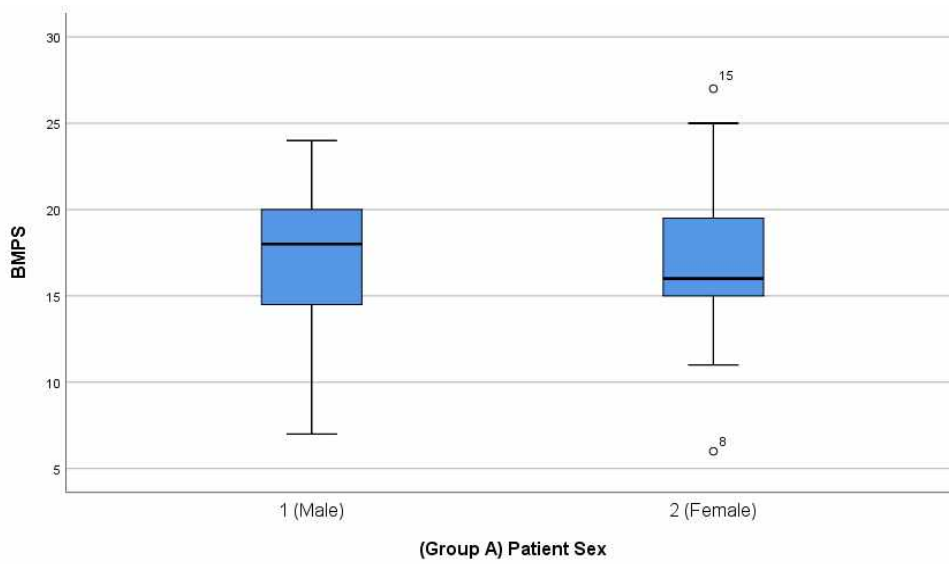


Figure 4. BMPS according to patient's gender in Group A.

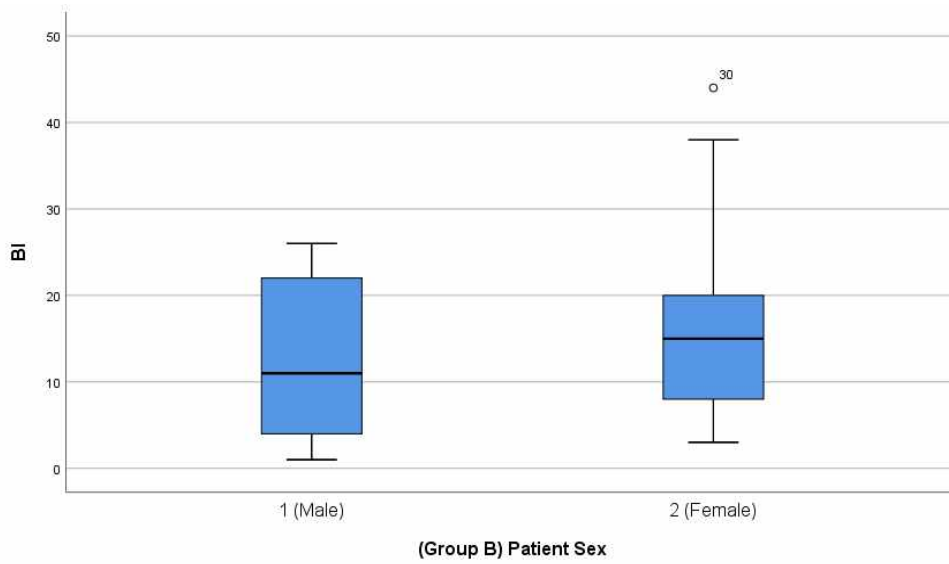


Figure 5. BI scores according to patient's gender in Group B.

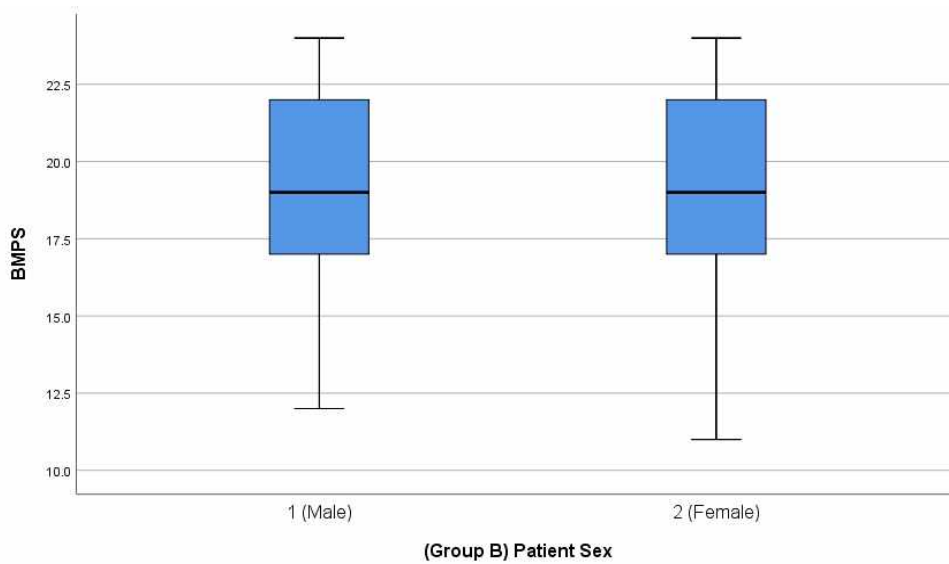


Figure 6. BMPS according to patient's gender in Group B.

Appendix

Questionnaire of Burden Interview

Please circle the response that best describes how you feel.
 (0: never, 1: rarely, 2: sometimes, 3: quite frequently, 4: nearly always)

Question	0	1	2	3	4
1. Do you feel that your relative asks for more help than he/she needs?					
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over your relative's behavior?					
5. Do you feel angry when you are around your relative?					
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?					
7. Are you afraid what the future holds for your relative?					
8. Do you feel your relative is dependent on you?					
9. Do you feel strained when you are around your relative?					
10. Do you feel your health has suffered because of your involvement with your relative?					
11. Do you feel you don't have as much privacy as you would like because of your relative?					
12. Do you feel that your social life has suffered because you are caring for your relative?					
13. Do you feel uncomfortable about having friends over because of your relative?					
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?					

16. Do you feel that you will be unable to take care of your relative much longer?					
17. Do you feel you have lost control of your life since your relative's illness?					
18. Do you wish you could leave the care of your relative to someone else?					
19. Do you feel uncertain about what to do about your relative?					
20. Do you feel you should be doing more for your relative?					
21. Do you feel you could do a better job in caring for your relative?					
22. Overall, how burdened do you feel in caring for your relative?					

*From: Bae, Shin, Kim, Kim, Yang,,et al., J Korean Soc Biol Ther Psychiatry, 2006;12(1):66-75.

Appendix

Questionnaire of Burden Interview (Korean version)

다음은 보호자들이 환자(자녀)를 돌보면서 경험할 수 있는 느낌에 대한 질문입니다. 각 질문의 내용과 같은 느낌이 얼마나 자주 있는가를 표시해 주십시오. 질문에 대한 옳고 그름은 없습니다.

(0: 전혀 그렇지 않다, 1: 아주 가끔 그렇다, 2: 가끔 그렇다, 3: 자주 그렇다, 4: 거의 항상 그렇다)

	0	1	2	3	4
1. 환자(자녀)가 필요 이상의 도움을 요구하신다고 느끼십니까?					
2. 환자(자녀)와 함께 보내는 시간 때문에 자신을 위한 시간은 충분하지 않다고 느끼십니까?					
3. 환자(자녀)를 돌보는 일과 직장이나 가정에서의 책임 사이에서 스트레스를 받습니까?					
4. 환자(자녀)의 행동 때문에 당황스럽습니까?					
5. 환자(자녀)와 함께 있으면 화가 납니까?					
6. 가족이나 친구들과의 관계에 환자(자녀)가 부정적인 영향을 미친다고 생각하십니까?					
7. 환자(자녀)의 미래가 어떻게 될 지 걱정됩니까?					
8. 환자(자녀)가 자신에게 의존적이라고 느끼십니까?					
9. 환자(자녀)와 함께 있으면 긴장됩니까?					
10. 환자(자녀)를 돌보는 일 때문에 자신의 건강에 문제가 생겼다고 느끼십니까?					
11. 환자(자녀) 때문에 자신이 원하는 만큼 사생활을 갖지 못한다고 느끼십니까?					
12. 환자(자녀)를 돌보는 일 때문에 자신의 사회 생활에 어려움이 있다고 느끼십니까?					
13. 환자(자녀) 때문에 자신의 친구들을 집으로 부르는 것이 불편하다고 느끼십니까?					

14. 환자(자녀)가 자신에게만 의존하려는 것처럼 보이며, 다른 사람보다 자신이 돌봐주기를 원하는 것 같이 느끼십니까?					
15. 자신을 위해 쓰는 돈 이외에, 환자(자녀)를 돌보는데 필요한 돈이 충분하지 않다고 느끼십니까?					
16. 더 오랫동안 환자(자녀)를 돌볼 수 없을 것 같다고 느끼십니까?					
17. 환자(자녀)를 돌보는 과정 중에 자신의 생활을 통제하는 것이 힘들다고 느끼십니까?					
18. 환자(자녀)를 돌보는 일을 다른 사람에게 맡기기를 바라십니까?					
19. 환자(자녀)에게 무엇을 해줘야 좋을지 모르겠다고 느끼십니까?					
20. 환자(자녀)에게 더 많은 것을 해줘야 한다고 느끼십니까?					
21. 환자(자녀)를 돌보는 일을 더 잘할 수도 있었다고 느끼십니까?					
22. 전반적으로, 환자(자녀)를 돌보는 일을 얼마나 부담스럽게 느끼십니까?					

*From: Bae, Shin, Kim, Kim, Yang, et al., J Korean Soc Biol Ther Psychiatry, 2006;12(1):66-75.

Questionnaire of Bangor Mindful Parenting Scale

Please circle the response that describes what is generally true for you when parenting your child.

(0: never true; 1: sometimes true, 2: often true; 3: always true)

Question	0	1	2	3
1. I rush through activities with my child without being really attentive to him/her.				
2. In difficult situations with my child I can pause without reacting straight away.				
3. I tend to make judgments about whether I am being a good or a bad parent.				
4. I pay attention to how my emotions affect the way I act towards my child.				
5. I have trouble thinking of the right words to express how I feel about my child.				
6. It seems I am "running on automatic" without really being aware of what I'm doing with my child.				
7. When I have upsetting thoughts about my child, I am able to just notice them and let them go.				
8. I think some of my emotions towards my child are bad and I shouldn't be feeling them.				
9. I stay aware of my feelings towards my child.				
10. Even when I'm feeling terribly upset with my child, I can find a way to put it into words.				
11. I don't pay attention to what I'm doing with my child because I'm daydreaming, worrying or distracted.				
12. When I get upset with my child I am able to keep calm.				
13. Some of the thoughts I have about my child are negative and I say to myself that I shouldn't be thinking that way.				
14. I am aware of how my moods affect the way I treat my child.				
15. I'm good at finding the words to describe my feelings about my child.				

*From: Jones, Hastings, Totsika, Keane, Rhule. American Journal on Intellectual and Developmental Disabilities, 2014;199(2):171-85.

Questionnaire of Bangor Mindful Parenting Scale (Korean version)

다음 문장들은 부모가 그들의 자녀들과 소통하는 다양한 방식입니다. 자녀를 양육하는 부모로서 본인에게 가장 적절한 답변을 골라주십시오. 질문에 대한 옳고 그름이 없으며 본인의 주관적인 생각이 아닌, 직접적인 경험에 근거하여 답해주시길 바랍니다.
(0: 전혀 그렇지 않다; 1: 가끔 그렇다, 2: 자주 그렇다; 3: 항상 그렇다)

	0	1	2	3
1. 자녀와 무언가를 함께 할 때, 조금해 지시는 편입니까?				
2. 자녀와 함께 있을 때, 주변에서 곤란하게 한다면 바로 반응하지 감정 조절이 잘 되시는 편입니까?				
3. 본인이 좋은 부모인지 나쁜 부모인지 자주 생각해보는 편입니까?				
4. 감정에 따라 자녀를 대하는 방식이 달라지지 않는지 주의하는 편입니까?				
5. 자녀에 대한 마음을 간단히 설명해야 한다면, 적절한 표현을 찾기가 어렵습니까?				
6. 자녀에게 하는 행동이 무의식적이고 습관적이라고 느낄 때가 있습니까?				
7. 자녀에 대해서 속상할 때, 그 감정을 받아들이고 무시할 수 있습니까?				
8. 자녀에 대한 감정이 때로는 갖지 말아야 할 나쁜 감정이라고 생각합니까?				
9. 자녀에 대한 감정에 늘 신경쓰는 편입니까?				
10. 자녀에게 몹시 화가 날 때에도 대화로 해결하는 편입니까?				
11. 자녀와 함께 할 때, 다른 생각이 들거나 걱정에 휩싸여 자녀에게 집중을 하지 못합니까?				
12. 자녀에게 화가 날 때, 평온을 유지할 수 있습니까?				
13. 자녀에 대해서 부정적인 생각을 하면 안된다고 알고 있지만 어쩔 수 없이 그러한 생각이 들기도 합니까?				
14. 본인의 기분에 따라 자녀를 대하는 것이 달라진다고 생각합니까?				
15. 자녀에 대한 본인의 느낌을 잘 설명할 수 있습니까?				

*From: Jones, Hastings, Totsika, Keane, Rhule. American Journal on Intellectual and Developmental Disabilities, 2014;199(2):171-85.

국문초록

학령기 구순구개열 교정 환자와 일반 교정 환자의 보호자 간의 양육 부담에 대한 비교연구

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1. 연구목적

구순구개열이란 흔히 윗입술과 입천장이 모두 개열되어 있는 것으로 머리와 얼굴에서 발생하는 선천성 기형 가운데 가장 흔하게 발생한다. 다수 연구를 통해 선천성 질환을 가진 환자의 보호자들은 성격 특성이나 양육 부담에 있어 일반인 환자의 보호자들과 차이를 보이는 것으로 나타났다. 어린 연령대의 구순구개열 환자들은 보호자들과 함께 치과교정과를 내원하며 생애 전반에 걸쳐 지속적인 치과교정 치료 및 관리를 받아야 한다. 현재까지 구순구개열 아동을 양육하는 보호자들을 대상으로 하는 연구는 많지 않

은 실정이다.

본 논문의 목적은 구순구개열 교정 환자의 보호자들이 부모로서 갖는 심리적 양육 부담 및 스트레스를 일반 교정 환자의 보호자들과 비교해보고, 치과 임상가들이 다양한 특징을 가진 보호자들과 효과적으로 상호작용하여 진료의 상호 만족도를 높일 수 있도록 실마리를 제공하고자 한다.

2. 연구방법

본 연구는 2017년 8월 21일부터 9월 8일까지 3주간 서울대학교치과병원 치과교정과에 내원한 만 8 - 15세 이하의 교정 환자들의 보호자 (n = 80)를 대상으로 하였고 연구의 신뢰도를 높이기 위해 보호자의 성별은 여성으로 통일하였다. 실험 참여자들을 구순구개열 환자들의 보호자들과 (실험군, A군, n = 44), 일반 교정 치료를 받고 있는 환자들의 보호자들 (대조군, B군, n = 36)로 분류하였다. 대조군의 경우, 구순구개열을 포함한 기타 선천성 질환 병력을 가진 환자의 보호자들은 제외하였다. 자녀의 양육에 대한 스트레스 및 부담감에 초점을 두고 양육 부담의 정도를 측정하는 두 가지 설문지, Burden Interview (BI)와 Bangor Mindful Parenting Scale (BMPS)를 실험 참여자들에게 배포하였다. 두 설문지 모두 총점의 수치가 높을수록 양육 부담이 크다는 것을 의미하며 원문을 국내 실정에 맞게 번역하고 감수를 거친 자료를 사용하였다. 두 그룹 간 BI, BMPS

에 대한 통계적 비교 및 기타 분석은 통계적 유의수준은 0.05로 설정하고 진행하였다 (SPSS, Chicago, IL, USA).

3. 결과

1) BI와 BMPS 수치 모두 구순구개열 교정 환자들의 보호자들인 실험군이 일반 교정 환자들인 대조군에 비해 공통적으로 높은 평균값을 보였으나 (실험군, 대조군: BI 14.55 vs. 12.91, BMPS 18.13 vs. 17.32), BI와 BMPS 수치 모두 두 그룹 간 통계학적으로 유의미한 차이는 없었다 (BI, p value = 0.665; BMPS, p value = 0.448).

2) 실험군의 경우, 구순구개열의 종류 및 심각도에 따른 BI와 BMPS 수치를 비교해 본 결과, cleft lip, cleft palate, unilateral cleft lip and alveolus, unilateral cleft lip and palate, bilateral cleft lip and palate로 갈수록 BI와 BMPS 모두 대체로 수치가 상승하는 경향을 보였지만 구순구개열 종류 간의 통계학적으로 유의한 차이는 없었다.

3) 환자의 성별에 따른 BI, BMPS 수치를 분석한 결과, 실험군과 대조군 모두 환자의 성별이 여성인 경우에 BI와 BMPS 수치가 대체로 높았으나 환자 성별 간 통계학적으로 유의한 차이는 없었다.

4. 결론

본 연구 결과에 의하면 구순구개열 환자의 보호자들의 양육 부담이 일반교정 환자의 보호자들에 비해 다소 높은 경향을 보였지만, 통계학적으로 유의한 수준의 차이는 없었

다. 따라서 구순구개열 환자의 보호자들이 갖는 교정치료에 대한 부담의 정도는 일반 교정 환자의 보호자들과 비슷한 수준인 것으로 생각된다.

주요어: 구순구개열, 보호자, 부양 부담, 양육 부담, 교정 치료

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