

# Oral Health Quality of Life in Children with Cerebral Palsy: Parental Perceptions

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**Objective:** To assess the parents' perception of the oral health-related quality of life (OHRQOL) in children with Cerebral Palsy (CP) and compare it with normally developing children. **Study Design:** 63 children with CP were recruited from 8 disability centers, and 99 healthy controls were recruited from 5 elementary schools. The ages of the children in both groups were from 6-12 years. The Franciscan Hospital for Children Oral Health-Related Quality of Life (FHC-OHRQOL) was used to measure the OHRQOL and an oral examination was conducted in the schools/centers of the children to assess the teeth, gingival health, and oral hygiene. **Results:** The FHC-OHRQOL showed a significant difference in 3 out of 4 sections indicating lower OHRQOL in the CP group. The examination showed no significant difference in the dental and gingival health and in the level of oral hygiene. **Conclusion:** The OHRQOL of children with CP is significantly lower than that of normally developing children although the oral health status of children with CP is not significantly different from that of normally developing children.

**Key words:** Cerebral Palsy, quality of life, Oral Health.

## INTRODUCTION

Oral health is essential to the quality of life (QOL) and cannot be dissociated from general health.<sup>1</sup> In recent years, the concept of oral health-related quality of life (OHRQOL) has been introduced, expanding the array of traditional medical factors such as symptom and functional status that have been assessed when measuring QOL outcomes in health care settings.<sup>2</sup> The United States Surgeon General's report on oral health which defines OHRQOL as "a multidimensional construct that reflects (among other things) people's comfort when eating, sleeping, and engaging in social interaction; their self-esteem; and their satisfaction with respect to their oral health".<sup>3</sup>

Cerebral palsy (CP) is the most common form of neuromuscular disability affecting children.<sup>4</sup> It has been defined as a group of disorders of the development of movement and posture, causing activity

limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder.<sup>5</sup>

Information on the prevalence of CP in Saudi Arabia is scarce, but anecdotal evidence suggests that it is one of the most common disabling conditions in Saudi Arabia.<sup>6</sup> In a recent community based study it was found that the prevalence of CP in Saudi Arabia was 2.34 in every 1000.<sup>7</sup> In developing countries the prevalence of CP was found to range between 1.5 to 5.6 cases in every 1000, while it ranged from 2 to 2.5 in developed countries.<sup>8</sup>

Children with special health care needs (CSHCN) are at increased risk for dental disease. Neuromuscular, acquired, or genetic disorders often cause alterations or defects in skeletal and facial structures, tooth number and morphology, eruption pattern, and malocclusion. Medications required by CSHCN are known to cause intrinsic and extrinsic tooth discoloration, gingival enlargement, and xerostomia. Other medications containing sweeteners have been shown to increase the incidence of caries. It is generally agreed that this population of children has higher rates of poor oral hygiene, gingivitis, and periodontitis.<sup>9, 10, 11, 12</sup>

Several studies have examined caries and oral hygiene rates in individuals who have CP. In Riyadh, Al-Hammad and Wyne conducted a study on the caries experience and oral hygiene status of children with CP; They concluded from their study that caries experience of CP children in Riyadh was very high, and that very few of these children have good oral hygiene.<sup>13</sup>

A study done in China found that there was a significant difference in the gingival health status between preschool children with and without CP; the children with CP had higher plaque and gingival index scores. However, the caries experience was found to be

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similar between the 2 groups.<sup>14</sup> A Brazilian study found significantly higher decayed, missing, and filled tooth surfaces scores in children who had CP when compared with a control group of children who did not have disabilities. The investigators of this study also noted, however, that the children who had CP had higher plaque indexes, food residue, and rates of mouth breathing than the control group. This could help account for the higher caries rate.<sup>15</sup>

Very few studies were found measuring the OHRQOL of children with CP in Saudi Arabia. In light of this finding, this study aims to assess the parental perception of the OHRQOL for children with CP and compare them with normally developing children, and to assess the relationship between the OHRQOL and oral health of children with CP.

## MATERIALS AND METHOD

It is a case-control study that took place between the years 2011 and 2012. It involved a group of children with CP acting as cases (CP group) and a group of healthy, normally developing children acting as controls. The OHRQOL of the children in both groups was assessed using the FHC-OHRQOL and via telephone interview. The oral health was assessed for the children in both groups in terms of: dental caries, oral hygiene and gingival health.

The study design was evaluated and approved by the Research Ethics Committee of the Faculty of Dentistry in King Abdul-Aziz University.

The process of the study was explained to the parents through an informed consent; in case of agreement they were requested provide their phone number. Further explanation was provided during the telephone interview. In addition, the children's oral health conditions were discussed with the parents and upon request, parents were provided with a written report of their children's oral health statuses and treatment needs.

The sample consisted of a CP group and a control group. The process of assembling the CP group started by estimating the number of children with CP currently attending centers for CSHCN in Jeddah, Saudi Arabia. This was achieved by calling all the centers for CSHCN registered in the directory of the private and public centers in Makkah region issued in 2009 by King Abdullah bin Abdul-Aziz Disabled Children Association that received children with CP. This directory registered a total 32 centers. The 32 centers were assessed using the following inclusion criteria: providing a full rehabilitation program and having at least 5 children with CP at the time of the research. Centers that provided wrong contact information, were unwilling to participate in research work, reported poor parental cooperation in research work, had less than 5 children with CP, and provided physical therapy only and not a complete rehabilitation program were excluded.

A total of 8 centers met the criteria; an official letter explaining briefly the aim and process of the research was directed to the person in charge of each center. From the 8 centers, only children that met the following inclusion criteria were included:

1. Children diagnosed with CP and free from any other medical condition.
2. Boys and girls were included with ages ranging from 6-12 years.
3. Parents of the included children must be able to understand Arabic or English.

The control group included normally developing children recruited from 5, randomly selected regular private and public elementary schools for boys and girls from the same regions of the included centers for CSHCN. The children in this group fulfilled the same inclusion criteria of the CP group except for having any mental or physical disability.

## OHRQOL

The OHRQOL was determined using the FHC-OHRQOL questionnaire.<sup>2</sup> This instrument was published in English, and was translated by the researcher to Arabic in order for it to be applicable for use in our society. Prior to the use of the Arabic-translated version of the FHC-OHRQOL questionnaire, a pre-test survey was conducted to test the response of parents and to ensure proper understanding and comprehension of the questions. A sample of 8 children with CP who were attending in the university hospital pediatric neurology clinic was selected from the waiting area randomly. The examiner interviewed the mothers to fill out the questionnaire while they were waiting for their appointment. The response to the questionnaire was good and no alterations were required.

Unfortunately, due to the time limit, the Arabic translation of the FHC-OHRQOL could not be verified by testing, and to overcome this, it was decided that it would be administered through telephone interview to ensure proper understanding by parents. Two interviewers separately conducted these interviews. However, in order to avoid any ambiguity about any item on the questionnaire, a clear, mutual understanding of all items by the two interviewers was necessary.

The FHC-OHRQOL consisted of 4 sections and each item was rated on a 4-point scale: never (0); hardly ever (1); some of the time (2) or all of the time (3).

Section-I titled "child's oral problems/symptoms consists of 15 items. In this section the parents were asked to rate their children's current oral problems/symptoms including: spontaneous toothache, pain with hot or cool foods, pain with chewing, bad taste or bad breath, pain with sweets, bleeding with brushing or flossing, pain for no reason, broken teeth, dry mouth, painful bleeding gums, mouth sores, mouth blisters, swelling of the face, sore jaw, and headaches.

Section-II titled, "your child's daily life," contained 13 items where the parents were asked to rate the impact of their children's current oral health on their daily lives (i.e. "does your child have difficulty getting to sleep because of tooth/mouth pain?"). The items in this section were: difficulty eating, acts irritable, refuses certain foods, difficulty getting to sleep, wakes up from sleep, acts aggressive, difficulty paying attention, behavior trouble, avoids meeting people, misses school, experiences jokes about teeth, avoids smiling because of ugly teeth and avoids smiling because of missing teeth.

Section-III titled "parental concerns" consisted of 9 questions related to the parents' concerns about their children's oral health (i.e. "how often do you feel worried about your child's teeth or mouth interfering with their eating and nutrition?"). The items in this section were: eating and nutrition, anger about oral problems, schoolwork and attendance, missing sleep, parent missing work, change family plans, disrupt family life, unfinished chores and interferes with friendships.

In section-IV, a 13-cm visual analog scale (VAS) was used to answer each one of the 4 questions. The questions were:

1. What is your opinion of the appearance of your child's teeth and mouth?
2. How do you think your child's oral health is compared to other individuals of the same age?
3. How do you feel about your child's overall oral well-being?
4. How would you rate your child's overall QOL?

The VAS was constructed with "excellent" and "poor" at the ends of the scale and "good" in the center for questions 1, 3, and 4. For question 2, the VAS was anchored with "better than others his/her age" and "much worse than others his/her age" with "about the same as others his/her age" in the center. Parents were instructed to mark the answer on the copy of the questionnaire that was provided for them after the examination and to return it with the child the next day.

### Examination

A brief oral examination was conducted to assess the oral health status of the children. Examinations were conducted in the schools/centers of the children by 3 calibrated examiners after receiving parental consent. A flashlight was used to enhance visibility and disposable mirrors and gauze were used to facilitate the examination. All examinations were visual, and no probes were used to ensure the safety of the children and the examiners particularly with the challenging behavior of the children in the CP group.

The dental health was determined using the decayed, missing, filled teeth index (DMFT) for permanent dentitions and the decayed, filled teeth index (dft) for primary dentitions. Primary missing teeth were not recorded to prevent the misleading effect of exfoliation. The caries levels were categorized according to the WHO classification as very low (0-1.1), low (1.2-2.6), moderate (2.7-4.4), high (4.5-6.5) or very high (>6.6).<sup>16</sup>

The gingival health was determined using the Visual Periodontal Index.<sup>17</sup> The scoring for this index went as follows: (0) if the gingival tissue was healthy, appearing pink and firm; (1) if there was swelling and redness of the gingiva next to the tooth surface(s) either localized or generalized; (2) the gingival tissue appears bright red, gross loss of contour (form), and/or visible bleeding along gum margin.

The oral hygiene was determined using the Simplified Oral Hygiene Index (OHI-S).<sup>18</sup> The amounts of debris or calculus were recorded separately in the examination sheet and the Oral hygiene was considered good when the score was from 0-0.9, fair if the score was from 1-1.9 and poor if the score was >2.

### Statistical Analysis

All data were entered in the SPSS version 18, and the inferential statistical tests carried out were: the independent t-test for equal variance, the Welch's test for unequal variance, and the Chi square test to determine relationships between the variables. The Pearson correlation test was used to determine the correlation between the examination findings and the OHRQOL questionnaire and to determine the intra-examiner reliability. The Cronbach alpha was used for measuring the inter-examiner reliability. Significance was set at  $p < 0.05$ .

## RESULTS

To assess the inter-examiner reliability for recording the oral examination findings, the 3 examiners examined the teeth of 10 children. The same teeth were examined a week later. For the inter-examiner reliability the Cronbach's alpha was used and it was 0.999 for DMFT/dft, 0.998 for the Visual Periodontal Index, and 0.997 for the OHI-S indicating strong agreement.

### Response Rates

The response rates in the CP group were higher than the control group, of the 127 contacted children, 66 (51.9%) agreed to participate in the study, but only 63 (49.6%) completed the examination and FHC-OHRQOL. In the control group, of the 320 contacted children, only 110 (34.4%) agreed to participate and only 99 (30.9%) completed the examination and FHC-OHRQOL.

The mean age of the children in the CP group was 8.05 ( $\pm 2.098$ ) years, while the mean age in the control group was 9.19 ( $\pm 2.108$ ) years. There was no significant difference in the distribution of children between private or public schools or centers, and there was no significant difference in the gender distribution as well. The children included in the study were free from any medical condition other than CP in the CP group. This was confirmed through asking about the medical history.

### FHC-OHRQOL

Frequency percentages for the ratings of severity of the individual items in the FHC-ORQOL questionnaire sections I, II and III for both the CP and the control groups are presented in stacked bar graphs in figures 1, 2 and 3 respectively.

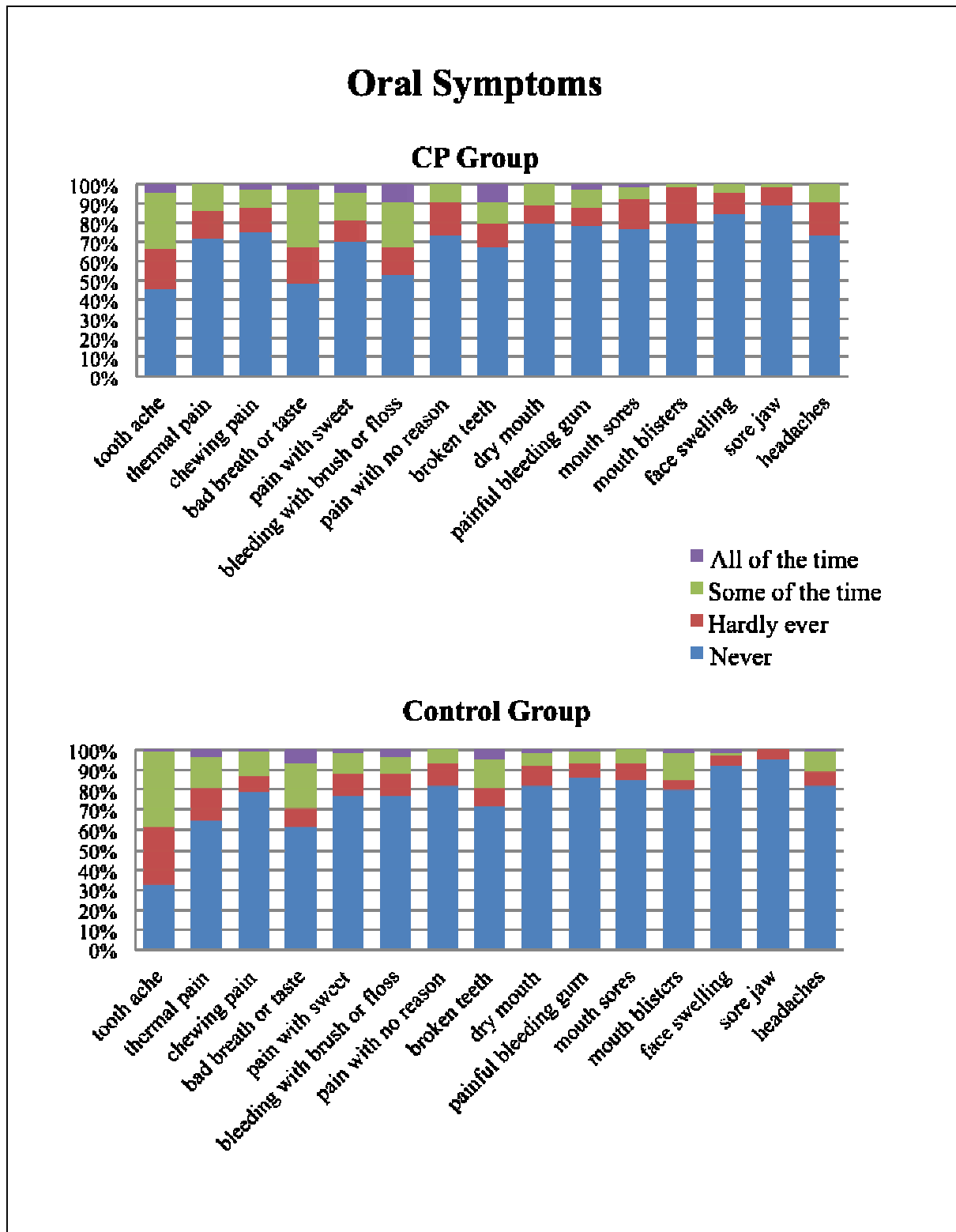
Figure 1 demonstrates that the most frequently reported as "all of the time" oral symptom or problem in the CP group was bleeding with brushing or flossing along with broken teeth. Spontaneous toothache and bad breath and taste were most frequently reported as "some of the time" complains. In the control group, bad breath or taste was the most frequently reported problem as an "all of the time" complain, while spontaneous toothache was the most frequently reported "some of the time" problem.

Figure 2 shows that the main daily life problem the parents encountered with the children in the CP group and the most frequently reported "all of the time" complain was the refusal of food due to a problem in the mouth of the child. Difficulty paying attention was the most "some of the time" reported complain. In the control group, refusal of food, difficulty paying attention, and behavior trouble were the most frequently reported as "all of the time" daily life problems, while refusal of food was the most frequently reported as a "some of the time" daily life problem.

Figure 3 demonstrates that (eating and nutrition) were the main concern that worried the parents in the CP group. In the control group however (changing the family plans) was the most frequently reported as "all of the time" concern. While concerns about eating and anger came as the most "some of the time" reported complains. Table 1 demonstrates the means of ratings of severity and the means for the number of positive findings for sections I, II and III for the CP and control group.

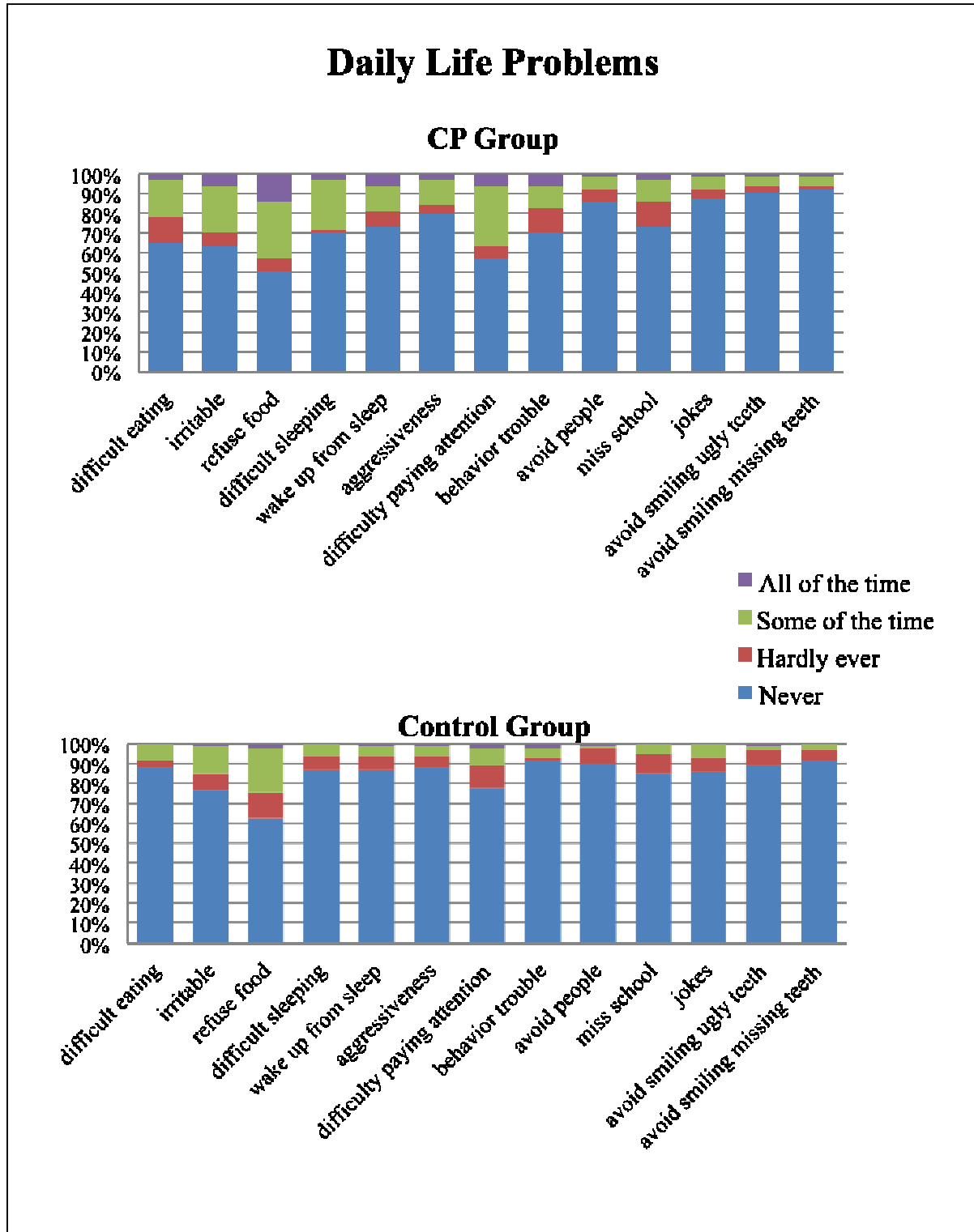
Regarding the first section of the questionnaire (Daily Symptoms), results showed no significant difference between the CP group and the control group in relation to the severity ratings of the symptoms experienced by the children ( $p = 0.204$ ).

Figure 1: The percentage distribution of the frequency of item ratings in the CP and control groups for section I (Oral Symptoms).



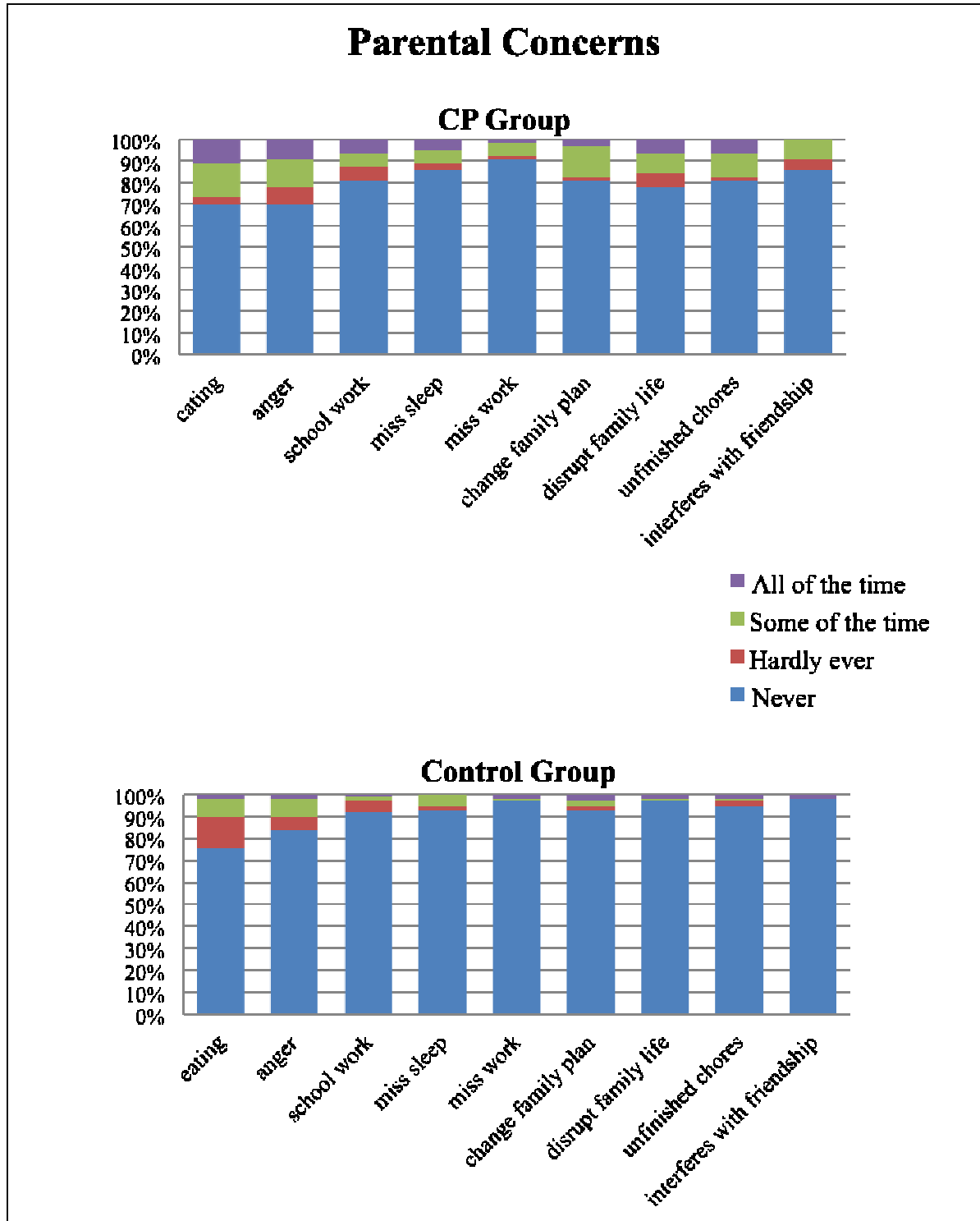
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Figure 2: The percentage distribution of the frequency of item ratings in the CP and control groups for section II (Daily Life Problems).



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Figure 3: The percentage distribution of the frequency of item ratings in the CP and control groups for section III (Parental Concerns)



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Figure 4: Means of rating of severity for the CP and control groups in sections I, II and III.

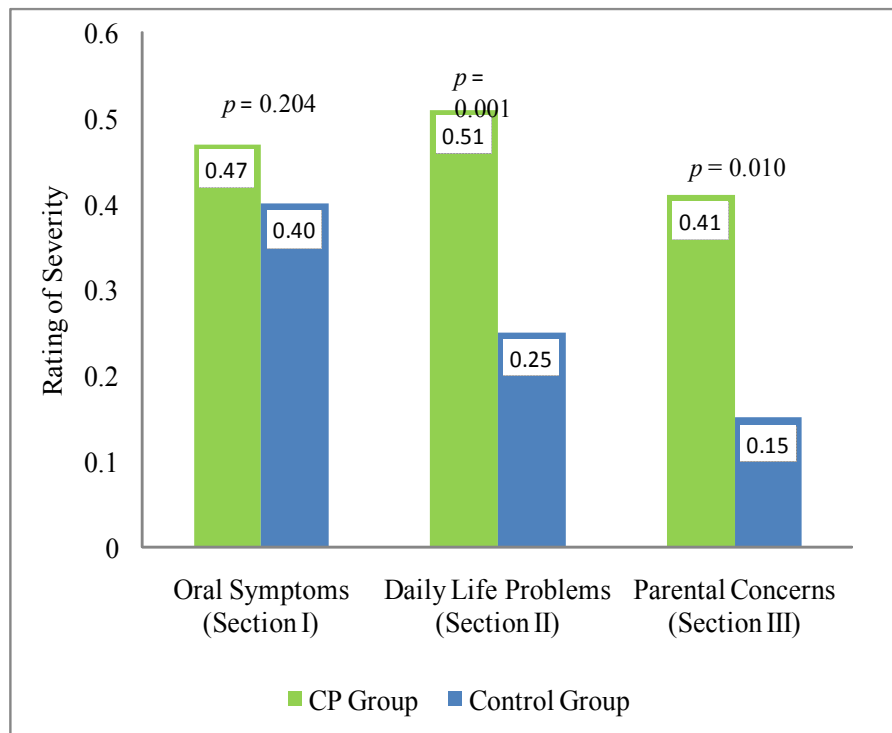


Table 1: Summary of the means of the severity ratings and number of positive findings in sections I, II and III for the CP and control groups.

OHRQOL	CP Group (n=63)	Control Group (n=99)	t-value	p-value*
	Mean (±SD)	Mean (±SD)		
<b>Rating of Severity</b>				
Section I (Oral Symptoms)	0.47 (±0.4)	0.4 (±0.35)	-1.28	0.204
Section II (Daily Life Problems)	0.51 (±0.55)	0.25 (±0.32)	-3.43	0.001
Section III (Parental Concerns)	0.41 (±0.7)	0.15 (±0.42)	-2.65	0.010
<b>Number of Positive Findings</b>				
Section I (Oral Symptoms)	4.40 (±3.96)	3.42 (±2.8)	-1.7	0.093
Section II (Daily Life Problems)	3.41 (±3.43)	1.93 (±2.44)	-2.98	0.004
Section III (Parental Concerns)	1.78 (±2.72)	0.70 (±1.48)	-2.89	0.005

\*Is significant when  $p < 0.05$ .

Table 2: Mean percentages of the scores for the CP and control group in section IV.

FHC-OHRQOL Section IV	CP Group (n=63)	Control Group (n=99)	t-value	p-value*
	Mean % (±SD)	Mean % (±SD)		
What is your opinion of the appearance of your child's teeth and mouth?	54.73 (±24.61)	64.87 (±25.83)	2.51	0.013
2. How do you think your child's oral health compares to other children of the same age?				
3. How do you feel about your child's overall oral well-being?	57.56 (±27.8)	66.54 (±24.6)	2.15	0.033
4. How would you rate your child's overall QOL?				
	53.22 (±23.78)	67.88 (±25.92)	3.69	0.000
	54.25 (±21.85)	83.93 (±20.8)	8.59	0.000

\*Is significant when  $p < 0.05$ .

In sections II and III (Daily Life Problems, Parental Concerns), a statistically significant difference was found ( $p=0.001$ ,  $p=0.010$  respectively). In both sections the CP group showed higher severity rating indicating lower quality of life in sections II and III (Figure 4).

The number of positive findings, section I didn't show any significant difference between the two groups, while in sections II and III there was a significant difference in the number of positive findings in both groups. ( $p=0.004$ ,  $p=0.005$  respectively). The cases showed higher number of positive findings in daily life problems and parental concerns (Figure 5).

Table 2 demonstrates the mean percentages of the visual analogue scale scores (section IV) for the CP and control groups. In this section of the questionnaire the results for the 4 questions were represented in the form of percentages. The scores on the 13 cm visual analog scale were converted to percentages. For all the questions in that section, there was a statistically significant difference between the CP group and the control group with the control group showing higher mean percentages, which indicates better quality of life.

In figure 6, the means of the scores for all the questions fell in the 55% range for the CP group. For the control group, the mean scores fell in the 65% range for the first 3 questions, but in the last question the score was much higher indicating a great difference in the estimated overall QOL between the two groups.

**Examination Results**

Table 3 demonstrates the percentage distribution of the oral examination findings for the CP and control groups. There was no significant difference found in the presence of dental caries, gingival health status, and level of oral hygiene between the two groups.

There was no significant difference between the two groups in regard to the means of the total DMFT (DMFT+dft), DMFT, dft, Visual Periodontal Index scores, and the OHI-S scores. The findings are summarized in Table 4.

**The Relationship between the FHC-OHRQOL and the Intra-Oral Indices**

In the CP group a weak, statistically significant relationship was found between the reported oral symptoms (Section I) and the total DMFT score ( $p=0.034$ ), while there was no statistically significant relationship found with the OHI-S and the Visual Periodontal Index scores ( $p=0.364$  and  $p=0.114$ ) respectively. The same relationship was found in the control group. In the CP group a medium strength statistically significant relationship was found between the reported parental concerns (Section III) and the OHI-S scores ( $p=0.005$ ). The findings related to sections I, II and III are summarized in Table 5. For section IV, relationship findings are demonstrated in Table 6.

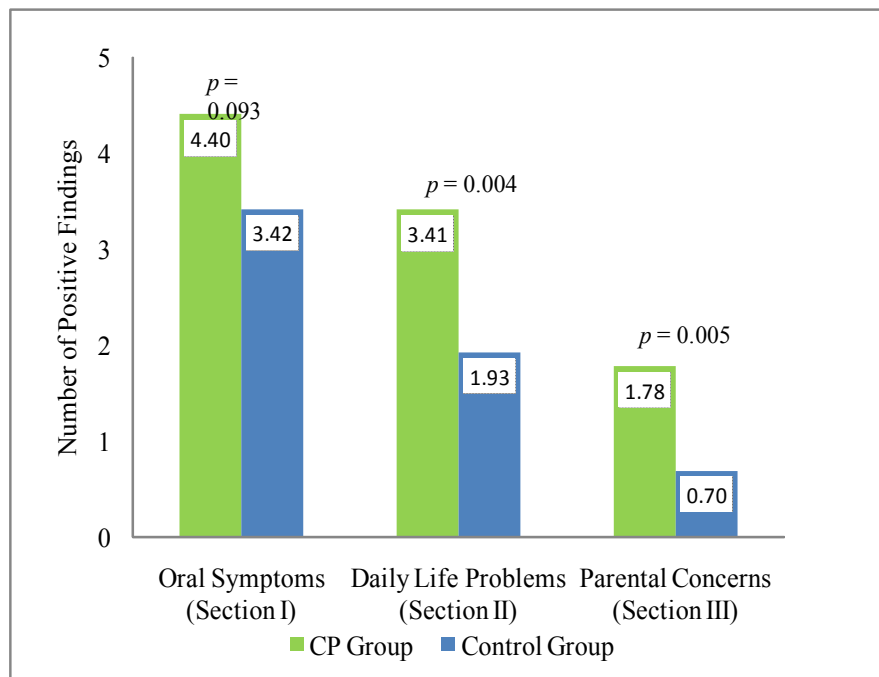
**DISCUSSION**

This research is a case-control study addressing the oral health and OHRQOL in children with CP from the parents' perspective. A comparison was made between the oral health and parents' perception of OHRQOL in the CP group and the control group. This was achieved by conducting a brief oral examination on the children in both groups and by the use of the FHC-OHRQOL.<sup>2</sup>

Very few researches were found concerning OHRQOL in children with CP in Saudi Arabia. The studies that were found mainly focused on the oral health status of these children,<sup>13, 19, 20</sup> and the parents' knowledge and attitude towards oral health.<sup>6</sup>

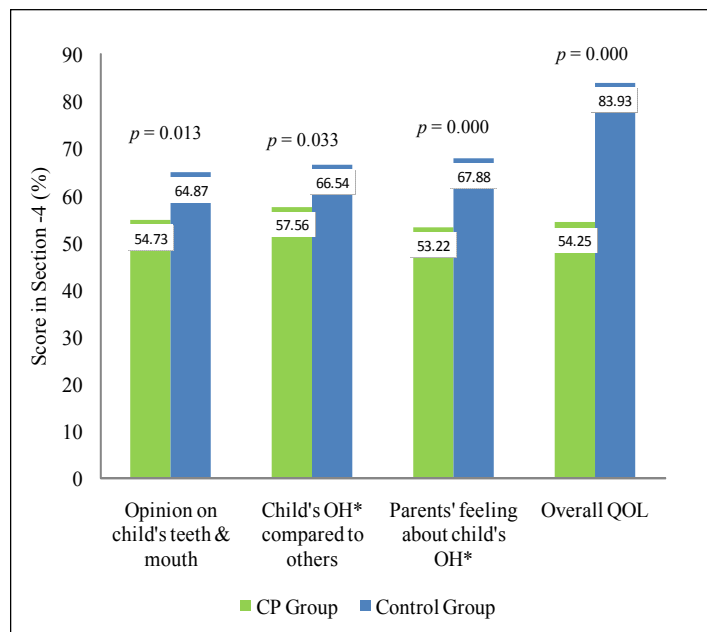
Children with CP, due to their medical condition may not have the ability to take care of their oral health,<sup>4</sup> and due to their cognitive status and limited communication ability may depend on their parents for recognition of their pain or distress. The pain they suffer from may be at an increased risk of staying unrecognized and underestimated.<sup>21</sup> Thus, special care should be given to their OHRQOL. This should be achieved through prevention and early detection of any oral health problem to avoid exacerbation and to lessen the way it may negatively affect their QOL.

**Figure 5: Means of number of positive findings for the CP and control groups in sections I, II and III.**





**Figure 7: Mean percentages of the scores in section IV for the CP and control groups.**



OH: Oral Health

**Table 3: Percentage distribution of the oral examination findings for the CP and control groups.**

Examination	CP Group		Control Group		X <sup>2</sup>	p-value*
	(n=63)	(%)	(n=99)	(%)		
<b>Caries</b>						
No	22	4.9	37	37.4	0.10	0.752
Yes	41	65.1	62	62.6		
<b>Gingival Health</b>						
Score (0)	9	14.3	18	18.2	0.42	0.517
Score (1)	54	85.7	81	81.8		
<b>Oral Hygiene</b>						
Good	9	14.3	26	26.3	3.43	0.180
Fair	46	73	64	64.6		
Poor	8	12.7	9	9.1		

\*Is significant when p<0.05.

**Table 4: Means of the intra-oral indices in the CP and control groups.**

Examination	CP Group	Control Group	t-value	p-value*
	Mean (±SD)	Mean (±SD)		
<b>Total DMFT**</b>				
	5.12 (±7.38)	4.28 (±3.37)	-0.99	0.326
<b>DMFT</b>				
	0.87 (±1.51)	1.32 (±1.7)	1.72	0.088
<b>dft</b>				
	3.6 (±3.64)	2.89 (±2.93)	-1.31	0.193
<b>Visual Periodontal Index</b>				
	0.86 (±0.35)	0.82 (±0.39)	-0.645	0.520
<b>OHI-S</b>				
	1.13 (±0.6)	1.14 (±0.66)	1.6	0.112

\*Is significant when p<0.05.

\*\* Total DMFT= DMFT + dft

**Table 5: The relationship between the intra-oral indices scores and sections I, II and III for the CP and control groups.**

Group	Test	Total DMFT	OHI-S	Visual Periodontal Index
<b>Section I: Oral Symptoms</b>				
CP	Pearson Correlation (r)	0.267	0.116	0.201
	Sig.2-tailed (p)*	0.034	0.364	0.114
Control	Pearson Correlation (r)	0.254	0.039	0.196
	Sig.2-tailed (p)*	0.011	0.705	0.052
<b>Section II: Daily Life Problems</b>				
CP	Pearson Correlation (r)	0.037	0.159	0.142
	Sig.2-tailed (p)*	0.772	0.214	0.266
Control	Pearson Correlation (r)	0.085	-0.010	0.158
	Sig.2-tailed (p)*	0.405	0.924	0.119
<b>Section III: Parental Concerns</b>				
CP	Pearson Correlation (r)	0.082	0.350	0.118
	Sig.2-tailed (p)*	0.522	0.005	0.358
Control	Pearson Correlation (r)	0.001	-0.045	0.151
	Sig.2-tailed (p)*	0.992	0.657	0.135

\*Is significant when p<0.05.

**Table 6: The relationship between the intra-oral indices scores and section IV for the CP and control groups.**

Section IV Group	Test	Total DMFT	OHI-S	Visual Peri-odontal Index
<b>What is your opinion of the appearance of your child's teeth and mouth?</b>				
CP	Pearson Correlation (r)	-0.244	-0.103	-0.348
	Sig.2-tailed (p)*	0.054	0.420	0.005
Control	Pearson Correlation (r)	-0.271	-0.095	-0.164
	Sig.2-tailed (p)*	0.007	0.348	0.106
<b>How do you think your child's oral health compares to other children of the same age?</b>				
CP	Pearson Correlation (r)	-0.226	-0.224	-0.100
	Sig.2-tailed (p)*	0.075	0.077	0.434
Control	Pearson Correlation (r)	-0.290	-0.070	-0.188
	Sig.2-tailed (p)*	0.004	0.491	0.062
<b>How do you feel about your child's overall oral well-being?</b>				
CP	Pearson Correlation (r)	-0.200	-0.126	-0.452
	Sig.2-tailed (p)*	0.117	0.324	0.000
Control	Pearson Correlation (r)	-0.184	-0.082	-0.231
	Sig.2-tailed (p)*	0.068	0.417	0.021
<b>How would you rate your child's overall QOL?</b>				
CP	Pearson Correlation (r)	-0.052	0.029	-0.207
	Sig.2-tailed (p)*	0.687	0.823	0.104
Control	Pearson Correlation (r)	0.004	0.033	-0.021
	Sig.2-tailed (p)*	0.969	0.746	0.833

\*Is significant when  $p < 0.05$ .

Recruiting an adequate sample for the study wasn't an easy task, especially for the CP group. From the list of centers for CSHCN in Jeddah, only two public centers were available, one of which was in the phase of changing their location and it was impossible to visit them at that time. The other center was the only public center used in this research and it provided a good number of children in the CP group.

The private centers for CSHCN in Jeddah may be abundant, but the numbers of children with CP especially were few; in some centers only 1 or 2 children with CP were found. Some of those centers reported poor parents' cooperation in research as observed from the center's previous experience with them. Those centers were excluded from the study sample for convenience.

The response rates in this study were higher in the CP group than that in the control group. This may indicate that centers for CSHCN are eager to participate in researches and studies for the benefit of their students.

In the centers for CSHCN, both private and public, it was found that the consent form would come back untouched in the child's backpack several times before it was returned filled out. Some centers had to call the parents to inform them that a consent form was sent with the child so they would pay attention to it. This shows that the parents of these children are stressed and although

many families cope well despite the added challenges of caring for a child with a disability, evidence suggests parents of children with CP are more likely to have a variety of physical and psychological health problems.<sup>22</sup>

The FHC-OHRQOL was chosen specifically because it was designed, and had been previously used on children with special needs, including children with CP.<sup>2</sup> This questionnaire had to be translated to the Arabic language in order for it to be used, but the translation was not tested for validity or reliability due to time limitation. This was overcome by conducting a pre-test survey to assess the proper understanding of the Arabic-translated version, and by developing a standardized scenario that answers the unclear areas. In addition, interviewing the participants by telephone to fill the questionnaire ensured their accurate understanding.

In the first section of the questionnaire, spontaneous tooth ache and bad breath or taste were the most frequently reported symptoms in the two groups when combining the "all of the time" and "some of the time" together. In the CP group bleeding with brushing and flossing was found to be equally frequent. These symptoms were found to be consistent with the examination findings in the two groups; high frequency of dental caries, mild to moderate gingivitis and fair oral hygiene. The findings of Beas-Ferrer showed that parents of CSHCN reported spontaneous toothache as one of the most frequent complains prior to oral rehabilitation, which is in agreement with the present findings.<sup>2</sup>

The most frequently reported daily life problem when combining the "all of the time" and "some of the time" together was refusing food in both groups. Which was in agreement with the findings of Beas-Ferrer who mentioned that refusal of food was one of the most frequent complains prior to oral rehabilitation.<sup>2</sup> In the CP group however, this frequency was found to be much higher. This is justifiable because it is common for children with CP to have feeding difficulties (Roger, 2004) additional tooth ache will defiantly make the process worse.

Based on the reports of the first and second sections, it comes as no surprise that the most frequent parental concern was about eating and nutrition in the CP group, this is in agreement with the findings of Beas-Ferrer.<sup>2</sup> Children with CP are at high risk for feeding and swallowing disorders that can have significant health implications, including limited caloric intake and acute and chronic malnutrition.<sup>23</sup> Successful management of this problem should definitely include regular dental visits and preventive dental care.

A significant difference was found in the of number of positive findings as well as the of severity rating between the CP and control group in the "Daily Life Problems" section and the "Parental Concerns" section of the FHC-OHRQOL questionnaire. Parents of children with CP reported higher numbers and more sever daily life problems and also reported higher concern for their children's oral health when compared to the parents in the control group. On the other hand, parents in the CP group reported similar findings in the oral symptoms section of the questionnaire as the parents in the control group. This suggests that although the children in the two groups suffer from almost the same oral health condition, parents in the CP group showed more distress and unease about their children's oral health and its effect on their lives. This finding emphasizes the fact that non verbal children (as

in children with CP), have difficulty expressing their complains, and their pain may stay unrecognized or underestimated in accordance to what Versloot et al. stated.<sup>21</sup> Consequently, parents of this group of children may feel obliged to always be alert to any sign of distress or discomfort.

The higher concern of parents in the CP group may be also justified by their awareness regarding their children's oral health. In a study testing the oral health knowledge of parents of children with CP in Saudi Arabia, Wyne found that the overall oral health knowledge and attitude of parents of CP children is satisfactory.<sup>6</sup>

According to the last section of the questionnaire (Section IV), the children in the CP group had lower QOL than the children in the control group. In all of the four questions, the mean percentage scores for the CP group always fell in the middle. The mean percentage scores for the control group were higher by around 10% in the first three questions regarding the oral health; however, when it came to the question about the overall QOL, the mean score was much higher in the control group.

Children in the CP group had lower OHRQOL and lower overall QOL, this is in agreement with the findings of Du et al., who found that the overall QOL and OHRQOL were significantly more compromised among children affected by CP than for preschool children without CP, highlighting the effects that CP has on general and oral health.<sup>24</sup>

The oral examination indices that were used in the present study were chosen for their ease of conduction on children with disabilities in the most inconvenient conditions. The examination had to be quick and completely painless because any irritation may cause the child to close his mouth and not open it again, sometimes a mouth prop had to be used in order to keep the mouth open for a while.

The presence of dental caries did not differ between the two groups, although the mean of the total DMFT (DMFT + dft) in the CP group was higher, but this was not significant. These findings are in agreement with the findings of Rodrigues dos Santos et al. who also found no significant difference in the DMFS between children with CP and children in the control group aged 6-11 years.<sup>15</sup> Pope and Curzon also didn't find difference in caries experience between children with CP and controls.<sup>25</sup> On the contrary, De Camargo and Antunes found that children and adolescents with CP suffer a higher burden of untreated dental caries than their non-CP counterparts.<sup>26</sup> In Nigeria, they found that the mean dmft and DMFT of children with CP were higher than that of the children in the control group.<sup>27</sup>

Regarding the oral hygiene of the two groups, there was no significant difference found. The results showed very similar mean OHI-S scores for the CP and control groups. The majority of the children in both groups were in the "fair" category. This was not in agreement with the literature that identified the oral hygiene in children with CP as worse than that in the control groups.<sup>15, 25, 26, 27</sup> This disagreement may attributed to the good oral care they received in the rehabilitation centers rendering them at a higher than expected level of oral hygiene.

Concerning the gingival health, the Visual Periodontal Index was chosen specifically for this research because it would give estimation on the gingival health without having to use a probe. Insertion of any intra oral instrument was really difficult in children

with CP especially as the examinations were not conducted in the clinic and the proper assistance and restraints were unavailable. The results of this study showed no significant difference in the gingival health between the two groups and both of them showed signs of mild gingivitis. This disagrees with Pope and Curzon and Du et al. who found that the gingival health in children with CP was worse than the children in the control group.<sup>24, 25</sup> This disagreement may be attributed to the fact that children in the control group had poor gingival health.

The small association found between the total DMFT and the severity of the oral symptoms reported may indicate that parents of children with CP have a good idea about the condition of their children's oral health, but the absence of association between the OHI-S and Visual Periodontal Index scores and the oral symptoms reported makes this possibility very weak. This may be explained by the fact that it may be difficult for parents of children with CP to identify poor gingival health and oral hygiene, while its always easier to identify cavitation or caries. It is also very difficult to know what a child with CP is suffering from in relation to their oral health.<sup>21</sup>

Parents of children with CP reported very few oral symptoms in the first section of the questionnaire compared to what is expected, and compared to the oral examination findings. This suggests that the parents of children with CP are not aware of the severity of their children's oral health problems, which contradicts what Wyne stated in his study on the oral health knowledge of parents of children with CP.<sup>6</sup>

The fact that there was no association found between the all examination results and the severity of daily life problems supports the idea that parents of children with CP may not be exactly aware of the extent of the oral health problem their children have, but they assume it is bad and are suffering from it in their daily life. This is also found in the third section where a correlation was found only with OHI-S and parental concerns, while there was no correlation found with the total DMFT and Visual Periodontal Index, indicating that the parents are highly concerned about their children's oral health based on assumption that it is not very well.

No significant association at all was found between the questions in section IV and the total DMFT or the OHI-S in the CP group. This also supports the previous statement that parents are concerned about their children's oral health and they know that their OHRQOL is lower than normal developing children even if they don't exactly know the extent of their children's oral health problems.

A negative significant association was found between the first and third question in this section and the gingival health status indicating that the opinions of the parents' on their child's oral health and their feeling about it were better as the Visual Periodontal Index scores were lower indicating good gingival health.

The OHRQOL in children with CP is low, and improving it is a shared responsibility that involves not only the parents of those children, but also the team of physicians, dentists, nurses, physical therapists and teachers who are an essential part of those children's lives. Raising the awareness towards oral health and its effect on the QOL is essential step to enhance their OHRQOL followed by prevention, screening and early detection of oral symptoms and problems. Every child should be a given a chance for the improvement of their QOL by all means irrespective of their disability, even a small improvement matters a lot to them.

## CONCLUSIONS

From this study, it was concluded that:

1. The OHRQOL of children with CP is significantly lower than that of normally developing children in 3 sections of the FHC-OHRQOL questionnaire:
  - The number and severity of the daily life problems.
  - The number and severity of the parental concerns.
  - The parents' opinions about their children's oral health status and their feelings about their children's over all oral well being along with their rating of the children's over all QOL.
2. The oral health status of children with CP is not significantly different from that of normally developing children in the same age group.
3. Parents' perception regarding their children's oral health was consistent with the caries activity detected by examination in both the CP and control groups.
4. There is a significant positive association between the parental concerns and the oral hygiene level in children with CP.
5. There are significant negative associations among items in section IV and the caries activity and the gingival health.

## RECOMMENDATIONS

In light of the findings of the present study, and for the purpose of raising the OHRQOL levels in children with CP and to overcome the concerns associated with their oral health condition the following recommendations are suggested:

1. To test the Arabic-translated version of the FHC-OHRQOL for validity and reliability of the translation in order for it to be available for use.
2. To train members from the centers for CSHCN and schools to identify oral problems and take action by referring the child to any dental care facility.
3. To increase the awareness of dental students and dental professionals towards the treatment needs and management methods of CSHCN. This could be achieved by encouraging them to visit the centers of this group of children to assess their needs, educate teachers and parents and guide them to achieve proper dental care.

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