Psychological Variables in Children and Adolescents with Cleft Lip and/or Palate

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Objective: *This review analyzes the psychological variables most frequently studied over the last 10 years in children and adolescents with cleft lip/palate (CL/P). Such variables are assumed to be the keys to these patients' psychosocial adjustment.* ***Study design:*** *Articles published from January 2007 to February 2017 were retrieved from PubMed to identify the psychological variables most commonly studied in children and adolescents with CL/P, irrespective of gender or type of cleft. The search terms were "cleft palate" and "psychology", with the operator AND.* ***Results:*** *Of the 324 articles retrieved, 26 met the criteria for inclusion in the review. The psychological variables most extensively studied over the years were children's social functioning, quality of life and ability to cope.* ***Conclusion****: While CL/P patients' quality of life was unanimously agreed to be affected, no consensus was found in the literature on social functioning or coping. In addition to the cleft, patient adjustment was reported to be governed by individual variables and mediators. The range of ages most frequently studied was 7 to 16.*

Keywords: *Cleft lip and/or palate, Psychology, Children, Adolescents*

INTRODUCTION

Cleft lip and/or palate (CL/P) are the most prevalent congenital genetic craniofacial defects.[1] Orofacial clefts can be subdivided into cleft lip (CL) with or without cleft palate, and isolated cleft palate (CP), where the lip and primary palate develop separately from the secondary palate.[2]

Most cases of cleft lip/palate are non syndromic, i.e., they occur unrelated to other major birth defects, developmental disorders or recognized syndromes. The incidence of CL/P varies with geography and ethnicity[1], with rates on the order of 1 *per* 700–1000 live births.[2-4] Genetic and environmental factors, particularly maternal smoking and the use of folic acid supplements, raise the risk of oral cleft.[5] The absence of a normal facial structure, speech impediments and the long-term stress of treatment may induce emotional distress that affects nearly every aspect of a patient's life.[6]

Social and emotional adjustment in individuals with CL/P is viewed as a developmental process that varies with the family environment, success at school and the person's ability to cope with the stress of growing up with the condition. These patients' psychosocial and cognitive functioning is the outcome of the complex interactions between genetic and environmental factors.[7] Patients with a facial disfiguration are not necessarily at a high risk of psychological problems on those grounds only. The impact of the defect varies depending on factors specific to the patient, their stage of development, their family and the environment.[8]

Collet and Speltz[9] (2007) contend that the progress in this area of research has been disappointingly limited in the last 10 years. Inter-study comparisons are difficult because very few longitudinal surveys have been conducted. Moreover, as these patients are not readily located and not all countries have databases that would help identify them, the studied sample sizes tend to be small.[4] Nonetheless, in the last 20 years, significant changes have been forthcoming in the diagnosis and treatment of children with craniofacial anomalies, with greater importance attached to factors such as age, gender and culture, although there has been a paucity of studies on the role of psychological intervention.[7]

The literature[9-12] reveals both a lack of uniformity in the assessment of the psychological variables involved and a wide spectrum of individual factors, along with social, cultural and environmental conditions. Klassen *et al*[10] (2012) did not identify any instrument designed specifically for CL/P patients. Richman *et al* [11] (2012) concluded that the wide variety of instruments used to measure behavior has resulted in outcome inconsistencies that are difficult

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to interpret. The methodology and methodological quality of studies are so varied that it is difficult to compare findings across studies.[9] Therefore, it is recommended to develop standardized measuring criteria, that would help identify CL/P-related problems.[9,12] More specifically, a mental health screening protocol for children and adolescents with orofacial clefts would help identify concerns and ultimately mitigate the stigma involved in admitting the possible existence of psychosocial issues.[12] The diversity of methods for measuring adjustment to CL/P has spawned conflicting research findings. The importance of studying the psychological adjustment to a CL/P should not be depreciated because it involves a host of interrelated elements.[12] The type of problem confronted (i.e., social, developmental, cognitive, behavioral, physical or emotional) must also be defined to address each cause separately rather than tackling the various problems as a single whole.[13]

The consensus among experts seems to be that children function better when their psychological adjustment is good.[13] This review consequently aims to analyze the psychological variables most extensively studied in children and adolescents with CL/P over the last 10 years. It also describes the measurement instruments used and possible age- and gender-based variations.

MATERIALS AND METHOD

A review was conducted according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. Papers published from January 2007 to February 2017 were retrieved from PubMed using "cleft palate" and "psychology" as the search terms with the operator AND. Search results were not limited by gender or cleft type. Articles involving the psychological variables studied in children and adolescents were included, irrespective of whether the parents or the children themselves were the source of the information. Studies covering patients on whom CL/P was associated with a syndrome, based on small samples (<25 individuals), samples including patients over 18 years of age or samples of parents only, involving surgical, logopedic or dental treatment, or described in articles not written in the English language were excluded. Reviews and meta-analyses were likewise excluded.

RESULTS

The aforementioned search strategy yielded a total of 324 articles. Of the 26 studies compliant with the inclusion criteria (Figure 1), 27% described the state-of-the-art, while 73% proposed using the results as a therapeutic aid. The most frequently analyzed variable was quality of life, followed by social problems and psychosocial adjustment, as shown in Figure 2.

Figure 3 lists the 26 studies conducted on CL/P children and adolescents by author, year, country, study topic, type of study, sample and control group characteristics, measuring instruments and results.

Scientific output in the area was highest in 2009, 2010 and 2015 (15% each), followed by 2012 and 2013 (11% each). In 62% of the studies, the children answered the questionnaires directly, and in 27%, both the children and parents were involved. In 8%, the parents responded to questions designed to assess their children's behavior, while in the remaining 4%, the data were sourced from a database of cleft lip or cleft palate patients. Half of the studies used a control group, and the other half did not specify this information.

A larger study of the subject was carried out in the USA (31%), followed by Norway (15%), England and Germany (11% each), Brazil (8%) and France, Sweden, Italy, Iran, Nigeria and Holland (4% each). Forty-two percent of the articles focused on children, 19% on adolescents and 39% on both.

After analyzing the results of the articles, it was obtained that 19% found greater social problems and another 19% lower quality of life; 16% did not find significant changes; 9% found a good psychological adjustment and another 9% low self-esteem; 6% showed higher rates of depression, another 6% high anxiety and 6% less psychological adjustment; and high emotional well-being and high self-esteem were each found in 3% of the articles.

Overall, 36 generic instruments were deployed to measure psychological variables, as well as one specific instrument used to assess cleft palate adolescents' quality of life (QoLAdoCleft Questionnaire). Some of the 37 instruments identified were used in more than one study. The Child Oral Health Impact Profile (COHIP), the Child Behavior Checklist (CBCL), the Satisfaction With Appearance (SWA) and the Child Experience Questionnaire (CEQ) were applied in 15% of the studies; 12% of the authors used the Self-Perception Profile for Adolescents (SPPA), the Strengths and Difficulties Questionnaire (SDQ) and the Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents, Revised Version (KINDL-R); and 8% used the Hopkins Symptom Checklist (HSCL), the Pediatric Quality of Life Scale (PedsQL), the Parenting Stress Index (PSI), the General Well-Being Scale (GWBS), KIDCOPE, BriefCOPE and the Family Impact Scale (FIS).

DISCUSSION

As noted earlier, the variables found to be the most accurate predictors of CL/P patient adjustment were social function, quality of life (QoL), and the ability to cope with the condition (coping). In turn, two of these study topics (social function and quality of life) were studied through specific instruments (SCS, HRQoL) or through indirect indicators of the topic (anxiety, depression, self-esteem).

A detailed description of the most prominent findings for each of those variables follows. A distinction is drawn in all cases between studies conducted in children and those involving adolescents in light of the subtle age group-related differences observed.

Social Function

As one of the so-called "social" pathologies[14] many authors associated CL/P with a number of inherent developmental and psychosocial issues: higher depression rates, attention deficit, hyperactivity, anxiety disorders, impaired social interaction, separation anxiety and learning disabilities.[8,15] The importance of distinguishing children by age groups was stressed in most papers, for adjustment patterns were reported to vary with the patients' stage of development.[16]

Preschool and elementary school children

Children with CL/P exhibited psychosocial problems such as anxiety, depression, social inhibition, low self-esteem, self-consciousness about appearance, poor social adjustment, low peer acceptance and classroom behavioral and learning disabilities.[3,6,17] Nilsson *et al*[5] (2015) suggested that children born with CL/P found psychosocial adjustment to be more difficult than their cleft-free

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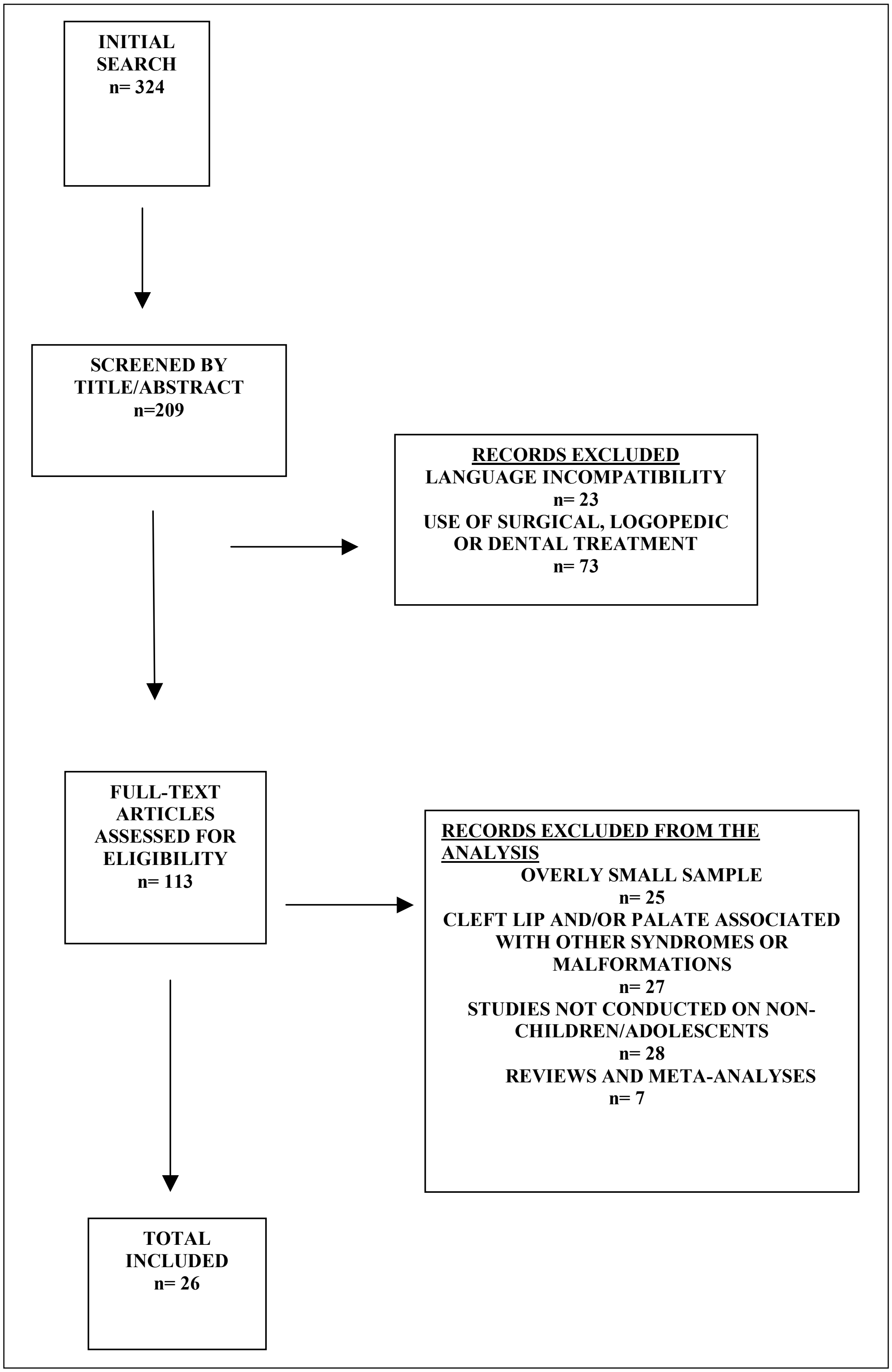

Figure 1. Flowchart showing articles identified, included or excluded and the reason for exclusion as appropriate

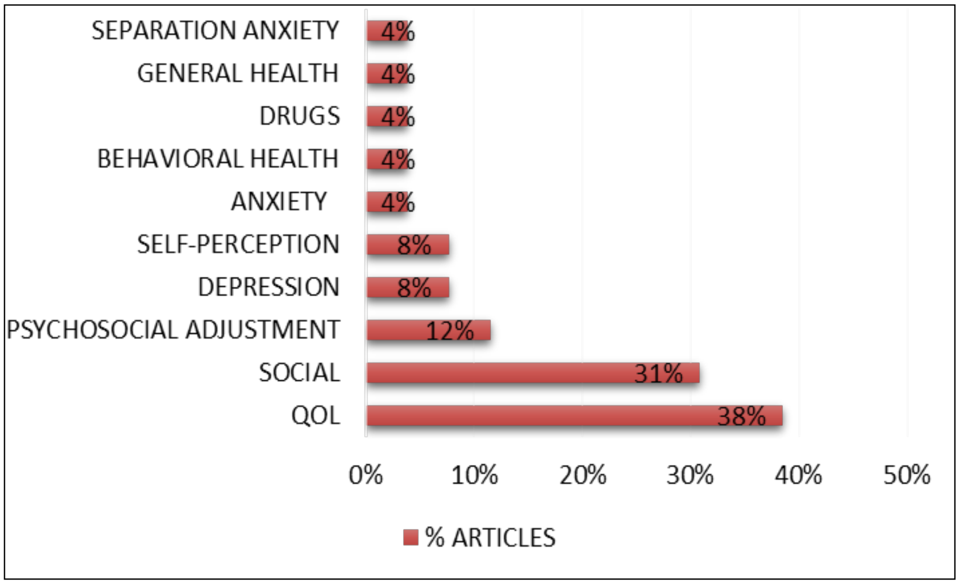

Figure 2. Frequency of variables

peers. Both esthetic factors and speech impairments were described to be the foundation of significant psychosocial challenges such as peer rejection, social isolation or bullying.[5] Self-perception was frequently deemed to be pivotal to adjustment because the links between subjective perception of physical appearance and self-esteem have been well established in the broader child and adolescent population, so cleft is a vulnerability factor for negative psychosocial experiences.[18] Elementary school children with CL/P were also found to have twice the normal rate of clinically severe social problems and be more likely both to receive negative responses to their approaches and to respond negatively when approached by others.[16,19]

The well-being of children with CL/P was more likely to be hampered by anxiety, bullying or taunting and their perceived different appearance.[2] Bullying was reported by approximately half of all CL/P children and young people in the United Kingdom and United States,[2] with boys being victims of bullying more frequently than girls.[20] Cleft children's "social attitude" was found to affect the way they were perceived by others. A lack of self-confidence at school due to verbal taunting and/or physical bullying induced some children to want to leave school as early as possible as a defense mechanism.[14]

Nonetheless, Kramer *et al* [21] (2008) showed that despite their low scores on self-esteem tests, children with CL/P did not always experience severe psychosocial problems. Collet *et al* [22] (2012) found only negligible psychosocial differences between children with and without CL/P, suggesting high resilience and good psychosocial adaptation among CL/P pre- and elementary school children. Feragen and Borge[23] (2010) contended that children with CL/P reported no more negative social experiences or dissatisfaction with appearance than children without facial differences.

Adolescents

Some authors described social experience as the best forecaster of adjustment for adolescents with a cleft,[24] while others reported social skill deficits in this age group.[16] Patients 15 to 18 years of age attached more importance to others' opinions than younger age groups.[2] Having CL/P was observed to raise the risk of psychotropic drug use.[5] Other studies, however, found emotional well-being and overall self-worth to be greater among adolescents with CL/P than in the reference group.[25] The impact of having a condition such as CL/P appeared to be low (at least at the age of 16) and no heavier than the impact of other concerns around appearance.[25] Berger and Dalton [26] (2009) observed that adolescents with a cleft reported more rewarding social experiences, greater satisfaction with their appearance and no greater adjustment difficulties than adolescents in the general population, which was the same as Santos Lima *et al* [1] (2015), who did not find significant changes in the levels of depression between these patients and the control group.

Some authors hypothesized that friendships and social acceptance can protect against depression in CL/P adolescents, finding in these patients more positive self-perceptions of appearance and less emotional distress.[25,27] Others deemed integration to contribute to acceptance of the pathology, while frequent taunting at school was observed to aggravate patients' negative self-perception.[14]

Quality Of Life (QoL)

Quality of life is an essential measure to evaluate every area of CL/P patients' physical and mental health, including oral health. QoL determinants include biological-physiological factors, symptoms, functional status and general health.[28]

Oral Health-Related Quality of Life (OHRQoL), a multidimensional construct, was used by some authors to identify how individuals' oral health affects their physical and psychological functioning and overall satisfaction with life.[29] CL/P patients' QoL was observed to be impacted by factors such as early diagnosis, the availability of support and information, surgical procedures and social acceptance both at school and by the population in general.[17] Health-related quality of life (HRQoL) helps health care professionals evaluate how patients are affected by disease, complications and treatment. Orofacial clefts were observed to significantly lower children's OHRQoL.[2] De Oliveira *et al* [17] (2015), however, found no

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Figure 3. Studies on psychological variables in CL/P children and adolescents.

STUDY TOPIC	VARIABLE	RESULTS	AUTHOR
Social Function	Emotional Well-Being	High	Feragen et al.[25] 2016*
	Depression	Low	Snyder and Pope.[16] 2010*
		Similar	Santos Lima et al.[1] 2015*
		High	De Oliveira et al.[17] 2015*; Fadeyibi et al.[8] 2012; Sagheri et al.[6] 2010*
	Self- Perception	High	Feragen et al.[27] 2010*
		Similar	Feragen and Borge[23] 2010
		Low	Lorot-Marchard et al.[14] 2015; Sagheri et al.[6] 2010*; Feragen et al.[18] 2009
	Self- Confidence	Low	Lorot-Marchard et al.[14] 2015
	Anxiety	Low	Snyder and Pope.[16] 2010*
		High	De Oliveira et al.[17] 2015*; Fadeyibi et al.[8] 2012
		High	Collet et al.[22] 2012*
	Social Adjustment	Similar	Feragen and Borge[23] 2010; Berger and Dalton[26] 2009
		Low	De Oliveira et al.[17] 2015*; Nilsson et al.[5] 2015*; Snyder and Pope.[16] 2010*; Murray et al.[19] 2010*; Feragen et al.[18] 2009; Boes et al.[3] 2007*
	Self-Esteem	Low	De Oliveira et al.[17] 2015* ; Sagheri et al.[6] 2010*
	Separation Anxiety	High	Tyler et al.[15] 2013
	Resilience	High	Collet et al.[22] 2012*
	Behavioral Difficulties	High	Berger and Dalton[24] 2011; Sagheri et al.[6] 2010*
Quality of Life	Health Related Quality of Life	Similar	De Oliveira et al.[17] 2015*
		Low	Eslami et al.[29] 2013, Ward et al.[2] 2013*; Damiano et al.[31] 2007
		No quantifiable data	Broder et al.[28] 2014
	Self- Perception	Low	Piombino et al.[30] 2014*
	Depression	High	Piombino et al.[30] 2014*
		High (in girls)	Feragen et al.[27] 2010*
	Anxiety	High	Piombino et al.[30] 2014*
	Behavioral health	Similar	Wehby et al.[32] 2012*
	Emotional Well-Being	Low	Bos and Prahl[33] 2011
	Self-Esteem	Low	Kramer et al.[20] 2009; Kramer et al.[21] 2008
Coping	Ability to cope	High	De Oliveira et al.[17] 2015*; Feragen et al.[27] 2010*
		High (in boys)	Berger and Dalton[24] 2011
		Low	Kramer et al.[21] 2008
	Resilience	High	Nilsson et al.[5] 2015*

*vs. control group

differences in HRQoL between individuals with CL/P and controls and attributed their findings to the greater attention paid to such patients by relatives and their access to interdisciplinary health services.

The variables observed to negatively affect CL/P patients' QoL included low self-esteem[21], depression and anxiety, troubled interaction with peers (due to negative self-perception) and physical appearance.[30] Some studies identified QoL differences between children and adults with orofacial cleft, noting that quality of life is affected by cognition and emotional development.[20]

Preschool and elementary school children

Tyler *et al* [15] (2013) reported lower QoL scores in CL/P children than in those without CL/P, particularly in connection with separation anxiety disorders (SAD), the rates of which were substantially higher in the former. The SAD symptoms observed included recurrent, excessive and developmentally inappropriate distress upon separation from parents or other attachment figures and even physical illness, predisposing children to other anxiety disorders and depression.[15] Fadeyibi *et al* [8] (2012) revealed high rates of depressive symptoms in children and adolescents with CL/P, which were more accentuated in 6- to 12-year-olds and more prevalent among girls. In contrast, some authors reported that elementary schoolchildren with CL/P had a higher QoL and higher self-esteem than a control group of similar ages [20] and no symptoms of anxiety or depression[16]. Although some surveys found boys to exhibit lower QoL than girls,[20] the latter were more deeply affected by oral health[29] and more dissatisfied with their appearance.[23] Possible age-related mitigation was identified, with higher HRQoL scores in 5- to 7- than in 2- to 4-year-olds with CL/P, followed by a decline at ages 8 to 12, when physical appearance acquired greater weight.[31]

Adolescents

The apparently fundamental role played by facial appearance in CL/P adolescents' quality of life may explain some of the gender differences reported in the literature. Feragen *et al* [27] (2010) showed that girls with CL/P were at a higher risk of depression. Eslami *et al* [29] (2013) found that the QoL of girls with CL/P was more affected by oral health, although no statistically significant gender differences were identified. Although children with oral cleft have similar behavioral health outcomes to unaffected children, more acute behavioral problems were identified among younger than older children and among boys than girls, and teenage girls were less satisfied with their appearance than boys of their age.[32] However, Bos and Prahl [33] (2011) found that cleft patients aged 12 years and older scored significantly lower on emotional well-being, with no significant gender differences, except for in girls who were slightly more worried about the treatment to come than were boys.

That the effect of CL/P on adolescents' oral quality depends on other personality variables may explain such divergence. Thus, resilience and a positive self-concept were found to affect QoL directly, and self-efficacy and self-esteem were regarded as protection skills, while depressive symptoms were described as having a negative effect on the QoL of adolescents with craniofacial anomalies.[28] Self-perception and social skills, fundamental variables for psychological health and self-esteem, were found to be affected by the way people interact with individuals with CL/P.[30]

Coping

CL/P heightens children's vulnerability to negative psychosocial experiences when they are struggling with emotional difficulties and an adverse self-perception.[18] Most CL/P patients were observed to be well adjusted and able to cope with the adversities confronted as a result of their condition.[17, 26]

The small number of studies found in the present review on coping primarily involved adolescents with CL/P who were observed to cope with bullying in a number of ways.[14] The attitudes described included verbal responses and on occasion physical responses or requests for help. Berger and Dalton [24] (2011) found gender to be a small but significant predictor of adjustment, with boys reporting greater adjustment difficulties than girls, for the behavior in the 11–16 age group was more externalized than girls. Boys were found to be more adept at developing defensive behaviors.[5] Some defense mechanisms entailed a desire to leave school as early as possible to reduce the exposure to taunting.[14] Therefore, although the presence of a visible cleft was not deemed to constitute a risk factor in itself, coping did appear to be a determinant of CL/P adolescents' quality of life.[27] Coping is probably more difficult due to CL/P children's esthetic appearance than due to functional limitations. [21] Some authors even suggested that having to cope with such situations may contribute to greater resilience and more effective functioning in adolescents with a visible cleft than in controls.[5,27]

CONCLUSIONS

The psychological variables most commonly analyzed by researchers studying CL/P children and adolescents included QoL (38%), social function (31%) and coping (12%).

- Quality of life was unanimously reported to be lower in these patients. Despite the fact that most authors contended that the problems were attributable to poor social adjustment, no consensus was found on social functioning and coping.
- The cohorts most extensively studied were those in the 7- to 16-year-old range. More studies were conducted on adolescents whose quality of life and social functioning were observed to be more deeply affected than children's.
- The effect of the variables studied in CL/P depends on mediating factors such as self-perception, anxiety, self-esteem, depression and resilience.

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