SOCIOEMOTIONAL DEVELOPMENT OF CHILDREN WITH CLEFT LIP WITH OR WITHOUT CLEFT PALATE (CL/P) ACROSS SOCIOECONOMIC BACKGROUNDS AND POTENTIAL IMPACTS ON FAMILIES: NARRATIVE REVIEW

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ABSTRACT

Cleft lip with or without cleft palate (CL/P) is a congenital developmental defect of the hard palate and is one of the most common congenital craniofacial abnormalities, resulting in common symptoms like feeding difficulties, hearing problems, and dental issues. In addition to these common physical implications, children with CL/P may also face challenges within the socioemotional domain. These challenges may also be worsened depending on individuals' social determinants of health: in particular, their socioeconomic status (SES). Database searches were conducted to understand the literature on the experiences of children with CL/P and their caregivers, and how these experiences intersect with SES. Barriers associated with SES include challenges regarding psychological impacts on caregivers, perception and stigma, socialization opportunities surrounding language, and access to medical interventions. These concerns emphasize the significance of considering the effect of socioeconomic implications on children with CL/P, highlighting the push for further research and resources to support their socioemotional development into adulthood.

KEY WORDS

cleft lip with or without cleft palate; socioeconomic status; child development; socioemotional development; psychological impact; stigma; socialization; medical interventions

INTRODUCTION

According to the Global Oral Health Status Report conducted by the World Health Organization in 2022, oral diseases affect 3.5 billion people worldwide, with orofacial clefts having a prevalence of 1 in every 1000-1500 births [1]. Amongst these is cleft lip with or without cleft palate (CL/P), which is the fourth most common congenital, hereditary craniofacial abnormality, often visualized as an opening in the upper lip and/or palate [2]. Typical oral development begins at week four of human embryogenesis and is complete by week ten: cleft lip develops due to the incomplete fusion of nasal processes with the maxillary process around week four, while a cleft palate forms due to the failed fusion of the palatal shelves around week eight [3]. The incomplete and/or failed fusion results in feeding problems from difficulties latching, hearing troubles from eustachian tube dysfunction, and articulation errors from hypernasality [4]. However, the clinical implications of CL/P extend beyond physical problems, affecting children's psychosocial development and social skills as well [4].

The variability of this condition also differs across gender, race, and geographic location. There is debate regarding the cause of gender disparities and CL/P, but studies generally present how biological male babies are twice as likely to have the disorder than biological females [1,2,5]. Overall, the highest burden of CL/P is reported to be in countries with low social development, where the most significant burden lies in Sub-Saharan Africa, Middle East/North Africa, and South Asia [6]. According to recent studies, there is contradictory evidence illustrating the connection between a higher incidence of orofacial clefts and lower socioeconomic status (SES), which refers to one's social and economic position in relation to others [2,7]; however, there is not much evidence on how SES influences early child development to adulthood. The scope of this paper is through a global lens, as the differing levels of social development across regions result in global disparities related to CL/P. The socioemotional developmental domain, which focuses on emotional regulation and relationship building [8], was chosen since CL/P can be linked to an increased risk for social problems [9]. Consequently, the socioemotional effects should be targeted in tandem with existing physical interventions when it comes to managing CL/P. While this developmental defect can be divided into cleft lip only, cleft palate only, or cleft lip with cleft palate, the term "CL/P" was most frequently used in the literature to refer to the disorder and will be employed to best encompass the condition. This article aims to explore how CL/P affects children's socioemotional development and their respective implications on caregivers, within the context of different socioeconomic backgrounds.

METHODS

Database searches were conducted while grey literature was consulted. Searches in PubMed, OVID Medline, and the Web of Science detailed the socioemotional challenges experienced by children with CL/P. Specific keywords like ["cleft lip" OR "cleft palate"], ["socioemotional development"], and [child*] were used to explore the connection between SES and implications of CL/P development. We included articles that targeted the socioemotional outcomes of CL/P on children and the psychosocial impacts on their caregivers. The population chosen is the central focus of this article, as examining affected individuals allows the discussion to remain grounded in lived experiences. As CL/P is a multifaceted condition that overlaps many domains, the scope of this paper is rather broad to act as a more comprehensive overview. In addition to peer-reviewed journal articles, grey literature was consulted as well to reflect current care models and policy frameworks. Furthermore, all included articles are in English, allowing authors to critically appraise and interpret the material without translation bias. Databases were searched for results up to February 2025 to best reflect contemporary trends in healthcare delivery and epidemiological patterns. All information from literature reviews and grey literature was ultimately synthesized in the creation of this article.

IMPLICATIONS OF SES

Across race and ethnicity, the prevalence of CL/P is highest among Asian (0.82-4.04 per 1000 live births) and American populations (0.9-2.69 per 1000 live births), and lowest among African-American populations (0.18-1.67 per 1000 live births) [1,5,10]. Based on the Global Burden of Disease Study from 2019, the global prevalence rate per geographic location is highest in South Asia, followed by Africa, East Asia, Europe, Latin America, and North America [6]. Examining the statistics further, the burden rate per 100,000 can be calculated using disability-adjusted life years (DALYs). DALYs measure the overall disease burden expressed in the number of years lost due to mortality or morbidity, where a greater number may be indicative of greater health loss, worse quality of life, or increased deaths [11]. The global burden of CL/P was estimated to be 6.85 and is distributed as follows: Sub-Saharan Africa (13.11), South Asia (10.84), Middle East/North Africa (6.81), East Asia/Pacific (4.37), Latin American/Caribbean (3.26), Europe/Central Asia (2.37), and North America (0.96) [6]. These statistics prompted the article's investigation, as a greater burden rate could be traced back to systemic socioeconomic barriers. In turn, SES could play a role in a child with CL/P's typical socioemotional development, which will be examined through the following four challenges: psychological impacts on caregivers, perception and stigma, socialization opportunities, and access to medical interventions.

Psychological Impacts on Caregivers

The emotional toll on caregivers following the birth of a child with CL/P can be overwhelming. The evidence suggests that mothers often grapple with an intense combination of shock, self-blame, and sadness, interspersed with moments of acceptance and gratitude for their child's life [12]. Hlongwa and Rispel's article highlights a pervasive sense of guilt among caregivers, particularly those who associate the condition with their behaviours during pregnancy, such as smoking or alcohol consumption [12].

The practical demands of raising a child with CL/P are equally daunting. Feeding challenges necessitate constant attention and frequent hospital visits for specialized treatments, disrupting daily routines [12]. These demands are particularly burdensome for caregivers of rural or low-income backgrounds, where access to healthcare facilities often requires long, costly journeys. Hlongwa and Rispel's article further notes how caregivers, especially those who are unemployed, may struggle to afford public transportation, and how their repeated absences from work further jeopardize their financial stability [12]. The intersection of practical and financial stress underscores the disproportionate inequities affecting populations made vulnerable by systemic or structural factors.

Caregivers of lower SES are frequently challenged with chronic stress from financial struggles, unstable housing, and systemic injustices [13]. The blend of pressures can lead to elevated levels of depression and anxiety, making it even more challenging for them to respond sensitively to their children's needs [13]. The result is a cycle where caregiving stress feeds into the family dynamic, creating further strain [13]. On the contrary, for those of higher

SES, caregiving may often come with a unique kind of stress known as achievement-related stress, which arises from the increased demands of juggling both career and caregiving responsibilities, fueled by societal pressures to excel in both areas [14]. While this stress is real and impactful, caregivers of higher SES are typically better equipped to manage it due to accessible resources such as therapy, paid absences, and stress management programs that could help ease their burdens [14].

The gap in resource availability between caregivers of different SES levels significantly affects their emotional experiences. Although these gaps are non-specific to CL/P, they are highly generalizable to the situation faced by caregivers of children with orofacial clefts [15]. High SES caregivers generally enjoy better access to quality childcare, healthcare, and educational resources, which can relieve some of the caregiving stress; however, it also comes with increased demands for their child to succeed [16]. Meanwhile, low SES caregivers often find themselves without basic necessities, such as healthy food and access to education; this limitation consequently makes it hard for them to focus on long-term goals for their children [17].

Finally, guilt manifests differently for these two groups as well. High SES caregivers may worry that their job commitments take away from their caregiving, especially in a culture that celebrates "competitive parenting" and high achievement [16]. In contrast, low SES caregivers frequently feel guilty about not being able to provide the same material or developmental opportunities for their children, propelled further by societal stigma related to poverty, which can deepen their feelings of inadequacy [18].

Perception and Stigma

Stigma poses a social barrier for individuals suffering from CL/P across numerous communities. Prejudices concerning the disorder often originate from a misrepresentation and misunderstanding of the causes of CL/P [19]. For example, a systematic review conducted by Chung et al., found that many individuals in low-resource areas attribute CL/P to divine punishment, evil spirits, or eclipses [19,20]. This stigmatization often bleeds into societal beliefs by negatively affecting one's experience with marriage, education, and employment [20]. Those with CL/P struggle to find significant others and face bullying in schools and the workplace [20]. Additionally, children with CL/P may experience reduced self-esteem [21]. The lower self-esteem may then hinder their ability to be educated in community spaces, as they often experience alienation from peers or are refused admission due to fear of frightening other students [21]. The emergence of negative experiences ultimately hinders their social function.

Public perceptions further exacerbate psychological strains on caregivers, reeling from stress and burden imposed on their child. A study conducted by Zhang et al. highlights that many caregivers suffered from negative emotions such as social anxiety and depression within the first three months after birthing a child with any orofacial cleft [22]. Negative emotions stem from fear of rejection from peer groups, and caregivers experienced high levels of discrimination [22]. Along with these harmful experiences, many experienced a worsened well-being and life satisfaction [22]. Citing the fact that visible impairments affect their children's social lives, many caregivers sought for their children to receive corrective surgery to reduce social stigma. Additionally, an investigative study found that caregivers with only a junior high school education had a greater stigma perception than participants who had received a minimum college education [22]. While family and close friends often provide much-needed support, societal reactions—ranging from gossip to intrusive questions—can create additional distress [12]. Mothers, in particular, report feeling judged during postnatal clinic visits or public outings [12]. Additionally, fathers' responses varied with some providing support or emotional and financial assistance, whereas others denied paternity, distancing themselves and leaving the mothers with sole responsibility. [12]. The societal scrutiny often delays their willingness to bring their child into public spaces until corrective surgeries are done, reflecting the pervasive stigma caregivers must navigate [12].

Furthermore, a child's social and educational environment can play a major role in perception and stigma. In schools, many children felt unsupported by their teachers when teasing occurred [23]. Additionally, children diagnosed with CL/P experienced decreasing satisfaction with their appearance as they aged [19]. During middle school years, children with CL/P were affected by bullying, discrimination, and teasing [24]. These individuals felt a lesser sense of self as "normal" compared to their peers [24]. Through facilitation of positive school transitions, support from clinical teams and implementation of teacher training can help to improve childhood experiences for those with CL/P [25]. In caregivers from Canada, the perceived stigma impacted the caregiver-child dynamic; resultantly, this leads to overprotectiveness or heightened sensitivity [26]. Overall, stigmatization and negative perceptions are a common experience for those suffering from CL/P that hinders their own emotional well-being.

Socialization Opportunities for Language Development

Several reports observe that children with CL/P experience delayed expressive language, as showcased through slower sound acquisition and limited sound inventory in early infancy [27-29]. These challenges with speech production experienced by children with CL/P can be attributed to altered oronasal structures, orofacial growth, and learned neuromotor patterns in infancy [27]. Furthermore, speech challenges can be distinguished as obligatory or compensatory [27,30]. Obligatory difficulties are due to structural deformities and cannot be treated until anatomical changes are first addressed, typically through surgery [27,30]. Alternatively, compensatory difficulties refer to the learned behaviours of children throughout their development based on maladaptive articulatory movements, which include changes in placements of articulation [27]. In cases of compensatory difficulties, these challenges persist even following surgery or structural changes [27]. With this in mind, existing reports state that speech therapy is the leading treatment, as it assists children in learning the placement of articulators and practicing appropriate airflow [27]. Further, it is recommended that these interventions begin as early as possible to improve communication skills and promote children's social development [27]. Beyond speech therapy, early intervention models encompassing language stimulation also promote language and sound production in children with CL/P [31,32]. Such programs, which include play therapy, caregiver-delivered intervention programs, and facilitated caregiver-infant programs, can help promote language and sound production by improving vocabulary and familiarizing children with various phonetics [31,32].

Concerning the relationship between children with CL/P's socialization and SES, current literature reports that lower SES households experience reduced access to speech therapy services, with potential reasons for this disparity including prohibitive out-of-pocket expenses and lack of insurance [33-35]. Furthermore, caregivers from lower SES households may face additional barriers in accessing such language development programs, beyond the costs associated with such programs [36]. These conclusions are from studies performed in North America; while the healthcare systems differ across countries, caregivers from across the globe report similar barriers to accessing such therapies for their children [34,36]. Many barriers exacerbate the financial costs of language programs in lower SES households, such as requesting time off from work, obtaining reliable transportation, arranging childcare for siblings, and direct and indirect costs associated with higher incidences of insurance coverage disruptions [36].

Another consideration is the neighborhood where a child is raised and the social opportunities available [37]. Toddlers raised in more affluent areas are observed to have greater access to educational resources, such as books and toys that facilitate intellectual development, which can help improve their ability to meet age-appropriate language and developmental milestones despite the challenges associated with an orofacial cleft [37]. As well, it is also documented that toddlers raised in more affluent areas likely have greater access to outdoor play spaces, museums, and other enriching activities, which can act as social facilitators for language development [37]. All these factors exemplify other avenues by which SES influences childhood experiences with CL/P [37].

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Access to Medical Care and Interventions

In addition to speech therapy, care for children with CL/P involves a multidisciplinary care team of specialists that work together to devise a treatment plan upon diagnosis [9]. Members may include, but are not limited to, a developmental pediatrician, audiologist, oral surgeon, orthodontist, plastic surgeon, and speech-language pathologist [38]. Managing CL/P is a continual and long-term process with multiple assessments (i.e., physical, hearing, feeding, speech, etc.) and reconstructive surgeries, with a lifetime cost estimated at $101,000 per child across the United States of America [39]. In Canada, the publicly funded healthcare system covers part of the medical expenses for CL/P repair, but this coverage does not include certain procedures and therapies [40]. There are, however, many non-government organizations (NGOs) providing financial aid and resources, such as Operation Rainbow Canada, which offers free reconstructive surgery and related health care [41]. Government programs also exist, like Ontario's Cleft Lip and Palate and Craniofacial Dental Program, assisting families coping with treatment expenses; however, this program has eligibility criteria, requiring patients to be an Ontario resident and OHIP member, have a CL/P diagnosis, and have sufficient residual craniofacial growth [42]. While existing NGOs and government programs could greatly ease the financial strain of CL/P, stringent and subjective eligibility criteria can still limit accessibility.

Notably, the medical costs associated with CL/P put families of lower SES at a great disadvantage. If CL/P is not treated appropriately in a timely manner, children may experience premature death and life-long difficulties in feeding, speaking, hearing, self-esteem, and psychosocial relationships [43]. The discrepancies with SES naturally create a degree of inequity between children from various SES backgrounds, affecting their socioemotional development and with lasting implications for later life. In fact, research has demonstrated that CL/P is undertreated in low- and middle-income countries due to late diagnosis and a lack of resources, consequently resulting in "extreme social stigma that has resulted in abandonment or infanticide" [44,45]. One study estimated there were "616,655 cases of unrepaired cleft lip and/or palate in 113 low- and middle-income countries in 2014" [46]. Further challenges faced by low-resource countries include lacking safe and sanitary facilities, long travel distances, or reduced specialist expertise. For instance, in South Africa, CL/P cases remain a burden due to a variety of factors, such as a low workforce density of dentists of 0.44 per 10,000 population [47]. The evidently sparse personnel in oral healthcare contributes to why 60% of children with CL/P in South Africa continue to suffer from a lack of care [47]. In addition to insufficient human resources, South Africa also faces a lack of data, increased social stigma, and negative environmental impacts, with areas of greater environmental pollution being linked to CL/P hotspots [47]. Not only do the listed challenges create financial and additional psychological burdens on caregivers, but it also places a heavy emphasis on NGOs. According to Sommerlad, approximately 75% of children with CL/P in low-income countries are treated by NGOs, emphasizing the need for better support and changes in the future focused on long-term sustainability [48]. A proposed method could entail designing training models in low-income countries to manage CL/P [49]. In this way, resources and personnel can be integrated to optimize patient care.

As mentioned, surgery is the immediate treatment option when it comes to CL/P interventions, resulting "in increased self-esteem, self-confidence and satisfaction with appearance" [50]. Furthermore, surgery can be seen as a way to increase physical attractiveness, as physical beauty and social acceptability are common problems faced by individuals with CL/P [50]. At the same time, there is also the possibility of dissatisfaction with surgery since not meeting high expectations could further exacerbate a child's self-satisfaction [50]. In turn, there is not a "one size fits all" for CL/P treatment, and the emphasis should be on the specific needs of the child and family. Ultimately, while costs differ based on an individual's CL/P condition, geographic location, and insurance status, there is nevertheless a financial burden that comes with the long-term care of CL/P that could affect successful medical interventions.

DISCUSSION

Numerous studies have identified how children with CL/P experience more significant difficulties in social environments [51]. Since communication skills play a role in social interaction, articulation errors associated with CL/P may increase the hardships children face in these settings. It has been hypothesized that children with this condition may fear negative judgement from others, "preferring to observe rather than participate actively in conversations" [51]. This concern is further exacerbated by the associated increase of harassment and discrimination, leaving significant potential for lasting sentiments of inferiority. Additionally, the guilt experienced by caregivers is a testament to the societal stigma and misinformation surrounding CL/P. These emotional challenges are compounded by long-term concerns about the child's speech development, educational opportunities, and overall well-being [12]. In turn, while speech difficulties may be the most apparent socioemotional developmental challenge experienced by children with CL/P, there are many other negative impacts that may influence their growth.

Currently, the economic effects of CL/P are not fully understood; however, that does not diminish the importance of examining their costs [52,53]. Families of lower SES often face additional burdens associated with psychological implications, stigma, and financial strain. These barriers could also limit socialization opportunities for children, affecting typical socioemotional development. Caregivers of lower SES may also be at greater risk of neglecting their child due to these increased burdens [54], ultimately affecting attachment styles and emotional regulation. Cleft diagnosis in individuals can also lead to decreased employability in adulthood due to social inequities, such as facing mistreatment in their workplace [55], further perpetuating a cycle of financial stress. Considering these factors, concerns around SES becomes a pertinent issue that needs to be addressed. Currently, government programs and NGOs are in place to assist families with the financial costs of CL/P therapy; however, not only is treatment inaccessible for everyone, but these physical and surgical operations do not address the overlooked social or psychological consequences that children with CL/P often face.

Our review article examined different sources detailing current patterns of the impacts of SES on CL/P; however, there is a possibility for selection bias and oversimplification of the issues. Narrative reviews lack a standardized, comprehensive methodology for study inclusion, so there is an inherent risk that the literature selected may reflect biases. The included studies were also not assessed for quality, furthering how the conclusions should be drawn with caution. The limitations of narrative reviews can result in an incomplete evaluation of all relevant studies and underrepresent conflicting findings. Nuances may have been missed, particularly in how SES interacts with intersecting factors like geographic location, healthcare access, ethnicity, or cultural stigma, which could all increase the risk of misinterpretation. As nuances are based on researchers' positionalities, transparency with the readers could further address the limitation. Finally, the subjective nature of this article can influence how general conclusions are interpreted and presented. Nevertheless, references were cross-checked, and discussions were held between authors to minimize these limitations to strive for a balanced and reflective summary.

CONCLUSION

Ultimately, this article provides a broad perspective of the issues surrounding SES and CL/P, synthesizing multiple perspectives to provide a general overview. At first, CL/P presents itself as if it only impacts the physical aspects of child development, but the challenges of CL/P impact child development far beyond appearances. With the integration of SES as a factor, potential impacts have risen that may influence typical socioemotional development. This article only discusses a few of the possible challenges associated with SES, and all potential influencing factors associated with families of children with CL/P should be considered together to best support them. More research should be conducted to provide possible alternatives to families of different socioeconomic backgrounds, accessing holistic multidisciplinary support from a team of specialists that best benefits all.

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