



IMPACT OF HAVING CHILD WITH CLEFT LIP AND PALATE ON PARENTS

By

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**Title: “IMPACT OF HAVING CHILD WITH CLEFT LIP AND
PALATE ON PARENTS”**

Aim of the study: The aim of the study to explore what are the impacts of having a child with cleft lip and palate on parents’ life.

Methodology: A cross-sectional descriptive study with the aid of a semi-structured questionnaire named Impact on Family Scale (IOFS) was used to collect data from the sample population. The study was conducted in 3 different hospitals across Dhaka city and one hospital in Chittagong city where health campaign for free surgical treatment of child with cleft lip and/ or palate was arranged by an organization names SNAD foundation. The main outcome measure was the level of impact a child with cleft lip and palate has on parents’ life and the level of impact on different domains of quality of life.

Result: The study explored that among the total 73 participants 95.90% (70) family was highly affected in the overall impact on life score measured by IOFS. 68.50% (50) high impact in social/ familial interaction domain, 71.20% (52) family had high impact in financial condition, 82.20% (60) family had high impact in Personal/emotional strain and 90.40% (66) family had high impact in coping which demonstrates parents had highest affect in coping and familial/ social domain was the lowest affected area.

Conclusion: This cross-sectional survey shows that looking after children with cleft lip and palate negatively impacts parents' and caregivers' life in multiple ways. The researcher believes that the findings of this study may assist speech and language therapists, as well as the interdisciplinary cleft management team.

Limitation:

Based on resources this is the very first study on the impact of having child with cleft lip and palate on parents. There were some limitations and barriers during conducting this study which follows:

- The researcher collected data from hospitals where free health campaigns for cleft lip and palate treatment was arranged in different districts across the country. Researcher only collected data from campaigns held in Dhaka districts.
- Researcher could not achieve the desired number of samples required for the study due to shortage of time and financial reasons.
- There was very little study on individual with cleft and their family in Bangladesh. The researcher did not find required literature to present the sufferings of parents of child with cleft. So researcher couldn't add any required information of Bangladeshi context.
- The study was conducted by purposive sampling method due to shortage of sample that meets the inclusion- exclusion criteria.

Recommendation

As it is first study in Bangladesh which explores impact of having a child with cleft lip and palate on parents, after completing the study the researcher explored that including some factors in the study would have make the study better. Recommendations from researcher for future study are-

- In Future studies researcher may consider to conduct the present study as a longitudinal study with larger population to verify the measure and to confirm and extend the findings that have been reported here.

- The present study can be conducted in future along with other instruments which measures parents' psychological impacts and health related complications.
- A Comparative Study of Quality of Life of Families with Children Born with Cleft Lip and/or Palate before and after Surgical Treatment can be conducted
- A comparison between QoL of parents and child with syndromic and non-syndromic cleft can be included.
- A comparison between QoL of parents and being diagnosed of child with cleft before birth and after birth can be included.
- In future study researcher may conduct present study with simple random sampling method.

References:

- Agnew, C. M., Foster Page, L. A., Hibbert, S., & Thomson, W. M. (2020). Family impact of child oro-facial cleft. *The Cleft Palate-Craniofacial Journal*, 57(11), 1291-1297. doi:10.1177/1055665620936442
- Aljohar, A., Ravichandran, K., & Subhani, S. (2008). Pattern of cleft lip and palate in hospital-based population in Saudi Arabia: Retrospective study. *The Cleft Palate-Craniofacial Journal*, 45(6), 592-596. doi:10.1597/06-246.1
- Antunes, L. S., Maués, C. P., Nadaes, M. R., Costa, M. C., Küchler, E. C., & Antunes, L. A. (2013). The impact of nonsyndromic oral clefts on family quality of life. *Special Care in Dentistry*, 34(3), 138-143. doi:10.1111/scd.12046
- Bailey, D. M. (1997). *Research for health professional* (2nd ed.). Philadelphia: F. A. Davis Company
- Baker, S. R., Owens, J., Stern, M., & Willmot, D. (2009). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *The Cleft Palate-Craniofacial Journal*, 46(3), 229-236. doi:10.1597/08-075.1
- Berger, Z. E., & Dalton, L. J. (2011). Coping with a cleft II: Factors associated with Psychosocial Adjustment of adolescents with a cleft lip and palate and their parents. *The Cleft Palate-Craniofacial Journal*, 48(1), 82-90. doi:10.1597/08-094

- Bordens, K.S., & Abbott, B. B. (2002). *Researcher design and methods: Research design and methods: A process approach*. McGraw-Hill. Retrieved from <https://psycnet.apa.org/record/2001-18329-000>
- Boulet, S. L., Grosse, S. D., Honein, M. A., & Correa-Villaseñor, A. (2009). Children with orofacial clefts: Health-care use and costs among a privately insured population. *Public Health Reports*, *124*(3), 447-453. doi:10.1177/003335490912400315
- Cassell, C., Daniels, J., & Meyer, R. (2009). Timeliness of primary cleft lip/palate surgery among children with orofacial clefts in North Carolina, 1995-2002. *The Cleft Palate-Craniofacial Journal*, *091202121239062*. doi:10.1597/08-154
- Chaurasia, B. D., Garg, K., Mittal, P. S., & Chandrupatla, M. (2017). *BD Chaurasia's human anatomy: Regional and applied, Dissection and clinical* (6th ed.). CBS & Distributors Pvt.
- Cox, T. (2004). Taking it to the Max: The genetic and developmental mechanisms coordinating midfacial morphogenesis and dysmorphology. *Clinical Genetics*, *65*(3), 163-176. doi:10.1111/j.0009-9163.2004.00225.x
- Danielson, C. B., Bissell, B. H., & Winstead-Fry, P. (1993). *Families, Health & Illness: Perspectives on coping and intervention*. Mosby.
- De Cuyper, E., Dochy, F., De Leenheer, E., & Van Hoecke, H. (2019). The impact of cleft lip and/or palate on parental quality of life: A pilot study. *International Journal of Pediatric Otorhinolaryngology*, *126*, 109598. doi:10.1016/j.ijporl.2019.109598
- De Cuyper, E., Dochy, F., De Leenheer, E., & Van Hoecke, H. (2019). The impact of cleft lip and/or palate on parental quality of life: A pilot study. *International Journal of Pediatric Otorhinolaryngology*, *126*, 109598. doi:10.1016/j.ijporl.2019.109598
- De Cuyper, E., Dochy, F., De Leenheer, E., & Van Hoecke, H. (2019). The impact of cleft lip and/or palate on parental quality of life: A pilot study. *International Journal of Pediatric Otorhinolaryngology*, *126*, 109598. doi:10.1016/j.ijporl.2019.109598
- DePoy, E., & L.N. (1998). *Introduction to research- Understanding and applying multiple strategies*. USA: Mosby
- Dixon, M. J., Marazita, M. L., Beaty, T. H., & Murray, J. C. (2011). Cleft lip and palate: Understanding genetic and environmental influences. *Nature Reviews Genetics*, *12*(3), 167-178. doi:10.1038/nrg2933

- Donker, P., Plange-Rhule, G., & Amponsah, E. K. (2007). A prospective survey of patients with cleft lip and palate in Kumasi. *West African Journal of Medicine*, 26(1). doi:10.4314/wajm.v26i1.28295
- Emeka, C. I., Adeyemo, W. L., Ladeinde, A. L., & Butali, A. (2017). A comparative study of quality of life of families with children born with cleft lip and/or palate before and after surgical treatment. *Journal of the Korean Association of Oral and Maxillofacial Surgeons*, 43(4), 247. doi:10.5125/jkaoms.2017.43.4.247
- Eslami, N., Majidi, M. R., Aliakbarian, M., & Hasanzadeh, N. (2013). Oral health-related quality of life in children with cleft lip and palate. *Journal of Craniofacial Surgery*, 24(4). doi:10.1097/scs.0b013e31828b743b
- Frankel, J. R., & Wallen, N. E. (2000). How to design and evaluate research in education
New York: McGraw
- Ghani, S., Mannan, A., Sen, S., Uzzaman, M., & Harrison, M. (2004). The problems of establishing modern cleft lip and palate services in Bangladesh. *The Journal of Surgery*, 2(1), 43-47. doi:10.1016/s1743-9191(06)60026-5
- Hasanzadeh, N., Khoda, M. O., Jahanbin, A., & Vatankhah, M. (2014). Coping strategies and psychological distress among mothers of patients with nonsyndromic cleft lip and palate and the family impact of this disorder. *Journal of Craniofacial Surgery*, 25(2), 441-445. doi:10.1097/scs.0000000000000483
- Hicks, C. M. (2000), Research methods for clinical therapists (3rd ed.). London: Churchill Livingstone
- Hupp, J. R., Ellis, E., & Tucker, M. R. (2019). *Contemporary Oral and maxillofacial surgery* (7th ed.). Elsevier.
- Kapp-Simon, K. A. (2006). A brief overview of psychological issues in cleft lip and palate. *Cleft Lip and Palate*, 257-261. doi:10.1007/3-540-30020-1_16
- Kramer, F., Baethge, C., Sinikovic, B., & Schliephake, H. (2007). An analysis of quality of life in 130 families having small children with cleft lip/palate using the impact on family scale. *International Journal of Oral and Maxillofacial Surgery*, 36(12), 1146-1152. doi:10.1016/j.ijom.2007.06.009
- Kramer, F., Baethge, C., Sinikovic, B., & Schliephake, H. (2007). An analysis of quality of life in 130 families having small children with cleft lip/palate using the impact on family scale. *International Journal of Oral and Maxillofacial Surgery*, 36(12), 1146-1152. doi:10.1016/j.ijom.2007.06.009
- Kramer, F., Gruber, R., Fialka, F., Sinikovic, B., Hahn, W., & Schliephake, H. (2009). Quality of life in school-age children with orofacial clefts and their families.

Journal of Craniofacial Surgery, 20(6), 2061-2066.
doi:10.1097/scs.0b013e3181be8892

- Kumar, M., Kumar, N., Murthy, J., Sharma, M., & Thamilselvan, P. (2015). Psychosocial issues of parents of children with cleft lip and palate in relation to their behavioral problems. *Journal of Cleft Lip Palate and Craniofacial Anomalies*, 2(1), 53.
doi:10.4103/2348-2125.150749
- Lawal, F., Taiwo, J., & Arowojolu, M. (2014). How valid are the Psychometric Properties of the oral health impact profile-14 measure in adult dental patients in Ibadan, Nigeria? *Ethiopian Journal of Health Sciences*, 24(3), 235.
doi:10.4314/ejhs.v24i3.7
- Locker, D., Jokovic, A., Stephens, M., Kenny, D., Tompson, B., & Guyatt, G. (2002). Family impact of child oral and oro-facial conditions. *Community Dentistry and Oral Epidemiology*, 30(6), 438-448. doi:10.1034/j.1600-0528.2002.00015.x
- Marazita, M. L., & Mooney, M. P. (2004). Current concepts in the embryology and genetics of cleft lip and cleft palate. *Clinics in Plastic Surgery*, 31(2), 125-140.
doi:10.1016/s0094-1298(03)00138-x
- Mednick, L., Snyder, J., Schook, C., Blood, E. A., Brown, S., & Weatherley-White, R. (2013). Causal attributions of cleft lip and palate across cultures. *The Cleft Palate-Craniofacial Journal*, 50(6), 655-661. doi:10.1597/11-300r1
- Nelson, P., Glenny, A., Kirk, S., & Caress, A. (2011). Parents' experiences of caring for a child with a cleft lip and/or palate: A review of the literature. *Child: Care, Health and Development*, 38(1), 6-20. doi:10.1111/j.1365-2214.2011.01244.x
- Rowland, A. (2008). Faculty opinions recommendation of socioeconomic status in relation to selected birth defects in a large multicentered us case-control study. *Faculty Opinions – Post-Publication Peer Review of the Biomedical Literature*.
doi:10.3410/f.1120725.576962
- Sankar, S. G., Viswapurna, P. S., & Vannala, V. R. (2011). *Textbook of orthodontics* (1st ed.). Paras.
- Stupia, L., Capogreco, M., Marzo, G., La Rovere, D., Antonucci, I., Gatta, V., . . . Tetè, S. (2011). Genetics of syndromic and nonsyndromic cleft lip and palate. *Journal of Craniofacial Surgery*, 22(5), 1722-1726. doi:10.1097/scs.0b013e31822e5e4d
- Wehby, G., & Cassell, C. (2010). The impact of orofacial clefts on quality of life and healthcare use and costs. *Oral Diseases*, 16(1), 3-10. doi:10.1111/j.1601-0825.2009.01588.x

World Health Organization Quality of Life (WHOQOL). (2020). *A Compendium of Tests, Scales and Questionnaires*, 671-678. doi:10.4324/9781003076391-184

[N.B. For better understanding of the study, please see hard copy & for any further information please contact: monirslt23@gmail.com]