

Quantifying the Burden of Malnutrition in Children with Orofacial Clefts

FINAL Report

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Executive Summary

Orofacial clefts have a profound impact on the quality of life and wellbeing of the estimated 4.62 million individuals across the globe who are living with them. While the most well-recognized outward symptom of cleft may be a physically-deformed upper lip, people living with unrepaired clefts have a number of other health challenges due to their condition. People with cleft regularly have difficulty with speech development and can develop respiratory infections more frequently than their peers due to the immune system in the nose and mouth not working as well as it could.

Another under-recognized consequence is the presence of a cleft can make eating, including breastfeeding, quite challenging. When people with unrepaired cleft – particularly young children – do not consume enough food, they are at high risk of developing of becoming underweight, a form of malnutrition that has been linked to increased risk of infections like diarrhea, measles, and pneumonia. Those who are malnourished are also at increased risk of complications of anesthesia and surgery and are known to heal less quickly. When malnutrition persists for a long time and/or is not reversed, it can lead to short adult stature (i.e. stunting) which has been linked with cognitive problems that lead to poor performance in school and lower lifetime earnings as well as earlier onset of health problems like diabetes, kidney disease, and obstructed labor for those who become pregnant as adults.

This report details the impacts of malnutrition in under-5 children with cleft throughout the world by merging the data collected on our patients by Smile Train clinical partners with the estimates and insights on the direct health consequences of malnutrition from the Global Burden of Diseases, Injuries, and Risk Factors Study. Malnutrition in the orofacial cleft population is categorically worse than that in the general population in all scenarios. At the global level, children younger than 5 years with a cleft condition were 2.15 times more likely to be underweight than the general under-5 population. There were nearly 200,000 under-5 children living with underweight in 2020 and more than 46,000 deaths related to malnutrition in under-5 children with cleft from 2000 to 2020. The full burden of malnutrition in cleft is likely even higher when taking into account the long-term consequences through a lifetime.

This report highlights both the enormous burden of malnutrition in those with cleft as well as highlighting opportunities to make a real impact in preventing malnutrition-related deaths in this highly vulnerable population. It underscores the tremendous importance of prevention (through nutrition interventions in pregnancy), identification, nutritional support, and surgical treatment for children with orofacial clefts throughout the world. Such measures are particularly relevant in the current global climate, as the COVID-19 pandemic has led to disruptions of routine vaccination and other health care services for children, while widespread food shortages contribute further stress to families.