Improving Nutrition for Children with Cleft Lip and Palate at Sally Mugabe Central Hospital: A Needs Assessment

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Abstract

Cleft lip and palate can significantly contribute to malnutrition as a result of considerable feeding difficulties. This study aimed to identify the challenges encountered by caregivers in providing optimal nutritional care for their children with cleft conditions. An exploratory qualitative design methodology was employed, utilising both the socio-ecological model and the UNICEF Conceptual Framework on the Determinants of Maternal and Child Nutrition. Data collection involved key informant interviews, focus group discussions, in-depth interviews, record reviews, and observation. Participants comprised caregivers of children with clefts as well as healthcare professionals. Many families affected by cleft disorders originate from economically disadvantaged backgrounds and experience food insecurity. Caregivers frequently lack knowledge regarding proper feeding practices, and socio-cultural norms significantly constrain the support available to female caregivers. Furthermore, the stigmatisation of children with clefts creates anxiety for mothers, particularly concerning breastfeeding in public settings. A notable lack of collaboration among stakeholders leads to fragmented nutrition services. In conclusion, caregivers encounter numerous challenges in achieving optimal nutritional care for their children with clefts, highlighting the urgent need for healthcare professionals to receive training in best practices for infant and young child feeding in the context of cleft.

Keywords: malnutrition, health services accessibility, health, knowledge, attitudes and practices, best feeding practices

Introduction

Orofacial clefts are common birth defects characterised by an opening in the upper lip (cleft lip) and/or roof of the mouth (cleft palate), with a higher prevalence in low-income countries(Delage et al., 2024). The World Health Organisation (WHO) estimates the global burden of children born with cleft lips and cleft palates at one in every 3,000 live births

(MOHCC, 2021). Prevalence is highest in Asians (1/500), intermediate in Caucasians (1/1,000), and lowest in African populations (1/2,500). Clefts of the lip have a 2:1 male-to-female ratio, while clefts of the palate have a 1:2 male-to-female ratio (Conway et al., 2015). In Zimbabwe, the incidence rate is estimated at 1,200 per live births (MOHCC, 2021)

A study conducted by Delage et al. in 2022 demonstrated a significant prevalence of malnutrition among cleft patients who were seeking surgical interventions in low- and middle-income countries (LMICs) (Delage et al., 2022). Cleft lip and palate (CL/P) can significantly contribute to malnutrition due to substantial feeding difficulties. If caregivers do not receive appropriate nutritional counselling on breastfeeding techniques for infants with a cleft soon after birth, this substantially increases the risk of malnutrition. Additionally, maternal malnutrition during pregnancy has been identified as a contributing factor to the development of CL/P in newborns, highlighting a complex interrelationship between nutrition and the formation of clefts (Duarte et al., 2016). Concurrently, the 2024 ZIMLAC report reveals concerning statistics regarding child malnutrition, indicating that the rates of underweight, stunting, and wasting among children under the age of five years are recorded at 9.8%, 27.4%, and 4.9%, respectively (UNICEF, 2024b). Notably, children under five with cleft conditions are more than twice as likely to experience malnutrition.

The World Health Organisation (WHO) and UNICEF have created the Global Strategy for Infant and Young Child Feeding (IYCF) to enhance the nutrition and health of young children. Key recommendations include: initiating breastfeeding within the first hour of birth; exclusively breastfeeding for the first six months; introducing safe complementary foods at six months while continuing breastfeeding for up to two years or beyond; and supporting mothers in making informed feeding choices (UNICEF & WHO, 2003). The principles of Infant and Young Child Feeding (IYCF) are universally applicable, regardless of whether a child has a cleft condition. The presence of a cleft does not alter a child's fundamental nutritional needs. In fact, children with clefts frequently require additional support to meet the IYCF standards effectively. Consequently, breastfeeding mothers should receive heightened guidance and resources to ensure that the specific nutritional needs of their child with a cleft are adequately addressed.

A cleft can influence the techniques employed to support Infant and Young Child Feeding (IYCF). Certain breastfeeding strategies for an infant with a cleft lip and/or palate include frequent feeding, ideally every two hours, while ensuring that the breastfeeding mother is in an

upright position, with the infant also positioned upright. Prior to breastfeeding, the mother should massage her breasts and apply gentle compression during the feeding process. In cases of a unilateral cleft, it is advisable to position the nipple away from the cleft, utilising a modified cradle hold. For infants with a bilateral cleft, the optimal practice involves holding the infant in an upright, face-to-face position using a cleft-modified football hold. If the infant exhibits a weak latch, the mother should adopt a dancer hand position, where the infant's chin rests on the webbing between the thumb and index finger to stabilise the jaw, while the remaining fingers support the breast. Additionally, the mother should encourage the latch by pressing the infant into the breast. It is crucial to note that infants with a cleft may ingest more air due to an inadequate seal; therefore, frequent burping is necessary (Smile Train, 2018).

Adequate nutrition is essential for a child to be able to undergo a safe cleft repair surgery (Duarte et al., 2016). In order for paediatric patients to be considered eligible for surgical intervention, it is imperative that consistent growth in both weight and height/length is demonstrated through comprehensive growth monitoring. Children who exhibit both stunting and wasting are at a significantly increased risk of mortality, quantified at 12.3 times higher than their counterparts (Olofin et al., 2013). A study conducted by Adams et al. (2025) concluded that perioperative undernutrition in initial cleft palate surgery was associated with a significant postoperative increase in fistula formation (Adams et al., 2025). Escher et al. (2021) also concluded that chronic malnutrition significantly increased the risk of fistula formation in patients with cleft palate. Preoperative strategies to manage this risk and influence surgical timing can avoid morbid and costly postoperative complications (Escher et al., 2021).

Limited access to reconstructive surgery in developing countries has led to the involvement of international organisations that provide surgical correction for patients with orofacial clefts. Based in New York City, the Smile Train organisation offers training and financial support for physicians and institutions to provide surgical procedures for patients with clefts of the lip and/or palate (Conway et al., 2015). In Zimbabwe, several organisations are actively engaged in advancing the cleft care programme. Among these are Global Cleft and Craniofacial Organisation, a locally registered non-governmental entity that collaborates with Smile Train to deliver vital services to those in need, as well as Shumiro Trust, Celebration Health, Operation of Hope, CURE Children`s Hospital of Zimbabwe, and the University of Zimbabwe. The initiatives implemented by these organisations are under the oversight of the Ministry of Health and Child Care.

A comprehensive examination of the records produced an informative report from Smile Train, which offered an in-depth analysis of data quality and nutritional status at the time of surgery in Zimbabwe during the period from January to November 2023. The findings derived from two hospitals revealed a concerning situation. Among the children who underwent surgical procedures, 15% were classified as wasted, while 22.95% were identified as stunted. Additionally, the analysis indicated that 38.8% of the records reflected inadequate registration practices as details for these children were not properly documented upon initial presentation.

Despite the risk associated with operating on a child with malnutrition, there is no standard of operation for organisations working on the cleft program to ensure that no child with either moderate or severe wasting goes in for surgery. Additionally, with the significant number of children affected by CL/P in Zimbabwe, which greatly contributes to malnutrition due to substantial feeding difficulties, there is no structured service to ensure early intervention and thus prevention of malnutrition. It was therefore essential to conduct a comprehensive investigation into the existing cleft care services informed by the experiences of caregivers.

The main objective of this study was to identify the challenges faced by caregivers in achieving optimal nutrition care for their children with clefts. The specific objectives were to comprehend and delineate the existing nutritional services available to children with clefts, to assess food accessibility within households affected by cleft conditions, and to evaluate mothers' nursing and feeding practices for infants with clefts. Additionally, objectives sought to identify sociocultural norms that influence the provision of adequate nutrition for these children, and to explore the existing governance structures related to cleft lip and palate care in Zimbabwe. The results were used to develop a theory of change, which would enable the establishment of a robust national nutrition program tailored to support paediatric care. This would ultimately address and mitigate the high levels of malnutrition prevalent among the paediatric population with CL/P.

Methodology

The research constituted an exploratory qualitative study rooted in phenomenology. It employed a conceptual framework amalgamating the socioecological model and the UNICEF Conceptual Framework on Maternal and Child Nutrition (UNICEF, 2024b) to comprehensively assess the needs of caregivers and children affected by CL/P. The socio-ecological model constitutes a theory-based framework that examines the intricate and

interdependent impacts across the different levels. The primary rationale behind the application of this model was to establish a solid foundation for an in-depth exploration of the needs at all levels. The conceptual framework is shown in the figure below.

Figure 1: Conceptual framework

The research was conducted from August 2023 to March 2024 at Sally Mugabe Central Hospital (SMCH) and the Global Cleft and Craniofacial Organisation (GCCO). Participants included caregivers of children with CL/P who had come to either SMCH or GCCO and healthcare professionals. Data collection methods included key informant interviews, in-depth interviews, focus group discussions, non-participant observation, and records review. Purposive sampling was employed for key informants, targeting individuals with specific knowledge or experience relevant to the study. Five key informants were selected from SMCH, three from the GCCO, and two from Shumiro Trust. For the focus group discussions with caregivers, maximum variation sampling was utilised to ensure the selection of a diverse group of participants attending either initial or follow-up visits. This approach facilitated the inclusion of participants who were as dissimilar from one another as possible, thereby capturing a wide range of perspectives and experiences. Additionally, twenty caregivers from the focus group discussions who expressed a willingness to participate in in-depth interviews and who felt they could share more than what was discussed in the group sessions were subsequently interviewed. Non-participant observation was conducted during a cleft camp held in August 2023, organised by Organisation A (the organisation was designated as Organization A in order to preserve confidentiality), where the measuring techniques employed by nurses and the criteria used to clear patients for surgery were observed. The data underwent deductive

thematic analysis utilising NVivo software. Approval was obtained from relevant authorities, including the Medical Research Council of Zimbabwe (MRCZ), under reference number MRCZ B/2430, as well as from the Chief Executive Officers of the Central Hospitals and the Director of Health Services for the City of Harare. Informed written consent was secured from all study participants.

Results

Qualitative analysis of the interviews and observations yielded four main themes.

Prevailing nutritional services provided to children with clefts and stakeholders involved in the cleft program

The study identified significant gaps in nutritional services for children with clefts in Zimbabwe. It was found that the provision of nutritional care was predominantly centralised in Harare and Bulawayo, which disadvantaged caregivers in rural areas. Key informant interviews revealed that the cleft programme in Zimbabwe engaged multiple stakeholders; however, the absence of collaborative efforts resulted in fragmented service delivery and a lack of a structured national nutrition program for children with clefts. Moreover, it was also highlighted that there was no centralised database or national surveillance system for children with clefts. During the observation conducted at the cleft camp organised by Organisation A, several measurement inaccuracies were identified. Notably, instances were observed where children were weighed while dressed in heavy clothing and wearing wet diapers. It was observed that for many patients, particularly those who had travelled long distances to attend the camp, their nutritional status was assessed based on a solitary measurement taken. During in-depth interviews, caregivers shared their experiences regarding their children's cleft journeys. Two caregivers highlighted that, when they first attended a camp to have their children screened and potentially operated on, they were informed that their children did not meet the necessary criteria. They were instructed to return the following year. Unfortunately, they did not receive any information about local organisations that could assist them. Out of the patients interviewed, five highlighted that a palate was not discovered soon after birth. Discussions conducted in focus groups revealed that the referral system for cleft care was inadequately developed, resulting in children presenting at healthcare facilities already suffering from malnutrition.

> "I was deeply distressed after delivering my baby because she was born with a cleft lip, and it was the first time I had encountered this condition. Although I had undergone an ultrasound scan during my pregnancy, the cleft was not detected. At

> the local clinic where I delivered, I received very little assistance regarding how to feed or care for my baby. As a result, I was referred to SMCH for further help, but my child had already lost significant weight." **Participant 1**

Accessibility of food and availability of resources within households affected by clefts

The in-depth interviews with families of children with clefts revealed a concerning finding, that is, most of these families came from economically disadvantaged backgrounds and significantly lacked access to essential resources like firewood and water. Focus group discussions further illuminated that this scarcity of resources not only led to inadequate access to nutritious food but also resulted in insufficient health services. They mentioned that they struggled financially, making it a challenge for them to travel to clinics or hospitals for the necessary assistance. The interviews with mothers underscored that this resource deficiency intensified their stress levels and placed additional pressure on them, ultimately affecting their ability to dedicate sufficient time to breastfeeding their infants.

Feeding practices of caregivers with children with clefts

The majority of caregivers expressed that they did not receive timely, sufficient counselling and nutrition education concerning the proper feeding of a child born with a cleft. Furthermore, it also came out that many infants were not breastfed within the first hour following birth. The discussions further revealed that the majority caregivers were advised to purchase specialised cleft bottles for their infants with clefts. Caregivers of children with cleft lip and/or cleft palate (CL/P) exhibited inadequate feeding practices that arose from a lack of knowledge and support from health care workers. It was found that their unfamiliarity with appropriate breastfeeding techniques for children with clefts resulted in the premature introduction of liquids (other than breast milk) and solids before six months of age, as they perceived that breast milk is insufficient or at risk of cessation. Moreover, in-depth interviews indicated that caregivers tended to prepare foods with inappropriate textures for the developmental stages of their children, believing that watery porridge is the most suitable option for children with clefts.

> "After giving birth to my child, I felt confused about whether to breastfeed. The healthcare workers did not seem sure either." **Participant 2**

> "I was advised to buy a specialised cleft bottle after I gave birth to my child with a cleft; however, it was too expensive, and I opted for the ordinary bottle." **Participant 3**

Sociocultural norms influencing the provision of adequate nutrition for infants with cleft conditions

The qualitative findings revealed that socio-cultural norms played a significant role in influencing the provision of adequate nutrition for children with clefts, with gender playing a crucial role in shaping these norms. From focus group discussions, it was revealed that support from husbands and family members after the delivery of a cleft baby was generally minimal as women were at times accused of infidelity, which resulted in giving birth to a child with a cleft. This was highlighted to significantly contribute to food insecurity as husbands were said to be the primary breadwinners in most families; their lack of substantial support further exacerbated the challenges faced by female caregivers in ensuring optimal nutrition care for children with clefts. This was also highlighted to be associated with stress, resulting in low breast milk production. Additionally, stigmatisation and discrimination of children with clefts led to challenges in accessing proper nutrition support for them.

> "Before my child had cleft lip surgery, I faced significant challenges in visiting the health facility. People made hurtful comments on the way, and once I arrived, many stared and asked me questions. This experience was so overwhelming that at times I would skip visits." **Participant 4**
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> "My husband abandoned me soon after I gave birth to our daughter who has a cleft. He was swayed by his family members who unjustly questioned the paternity of our child, claiming it was the first time such a condition had appeared in their family. As a result, I have taken on the responsibility of providing for and caring for our daughter on my own". **Participant 5**
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> "I overheard my neighbour saying she gave birth to an animal, and I was deeply distressed." **Participant 6**

Case Study 1: Nutrition and Surgical Intervention in a 1-Year-Old with Cleft Lip and Palate

Abigail entered the world facing the unique challenges of a cleft lip and palate, conditions that required extra care and attention to ensure she received proper nutrition. Sadly, her mother, overwhelmed and lacking the necessary support, struggled to initiate breastfeeding. This difficulty resulted in an early stop to breastfeeding, and they turned to infant formula as an alternative. Due to financial hardships, Abigail's mother was forced to overdilute the formula, which hindered Abigail's growth. When they first arrived at the GCCO, it was evident that Abigail was malnourished. She showed signs of moderate wasting, severe stunting, and was underweight. Her mother was using a bottle that was not adequately cleaned, and she expressed her worries about the challenges of accessing clean water. The situation was made even more difficult by the emotional weight of her partner's leaving after the birth of a child with special needs, leaving her to navigate this journey alone. In response to their situation, the GCCO team provided Abigail's mother with feeding tools, including a nifty cup that was easy to keep clean, alongside a supply of infant formula. They also took the time to guide her on how to properly prepare the formula while emphasizing the importance of hygiene. Recognising the pivotal role of nutrition, they educated Abigail's mother on introducing complementary foods at six months to further support her daughter's health. At nine months, Abigail was able to undergo her first cleft lip surgery. Though her surgery was delayed due to the late nutritional intervention and missed breastfeeding opportunities, there was a sign of hope. By the time she had her surgery, Abigail had made noticeable strides in her weight and length, indicating catch-up growth. Currently, Abigail is waiting for her cleft palate repair while continuing in the nutrition program. Despite the challenges posed by the distance to Harare, her local clinic has taken remarkable steps to collaborate with her in providing ongoing nutritional support. Abigail's journey is a testament to resilience, love, and the dedicated efforts of those around her.

Theory of change

Based on the results obtained, a theory of change (ToC) was developed to delineate a strategic approach for enhancing the nutritional status of children with cleft conditions. The ToC serves as a strategic framework that outlines how specific interventions can lead to desired outcomes in addressing the complex issue of malnutrition among children with cleft lip and palate (CL/P) in Zimbabwe. It emphasises the interconnectedness of various factors influencing the nutritional status of children with clefts, including healthcare access, caregiver knowledge, sociocultural dynamics, and resource availability. By detailing the causal pathways and assumptions that underpin the proposed interventions, the ToC can provide a clear roadmap for stakeholders to understand how targeted actions can effectively transform the nutritional landscape for affected children and their families. This comprehensive approach can improve immediate nutritional care for children with clefts and foster sustainable change. It is shown in Figure 2.

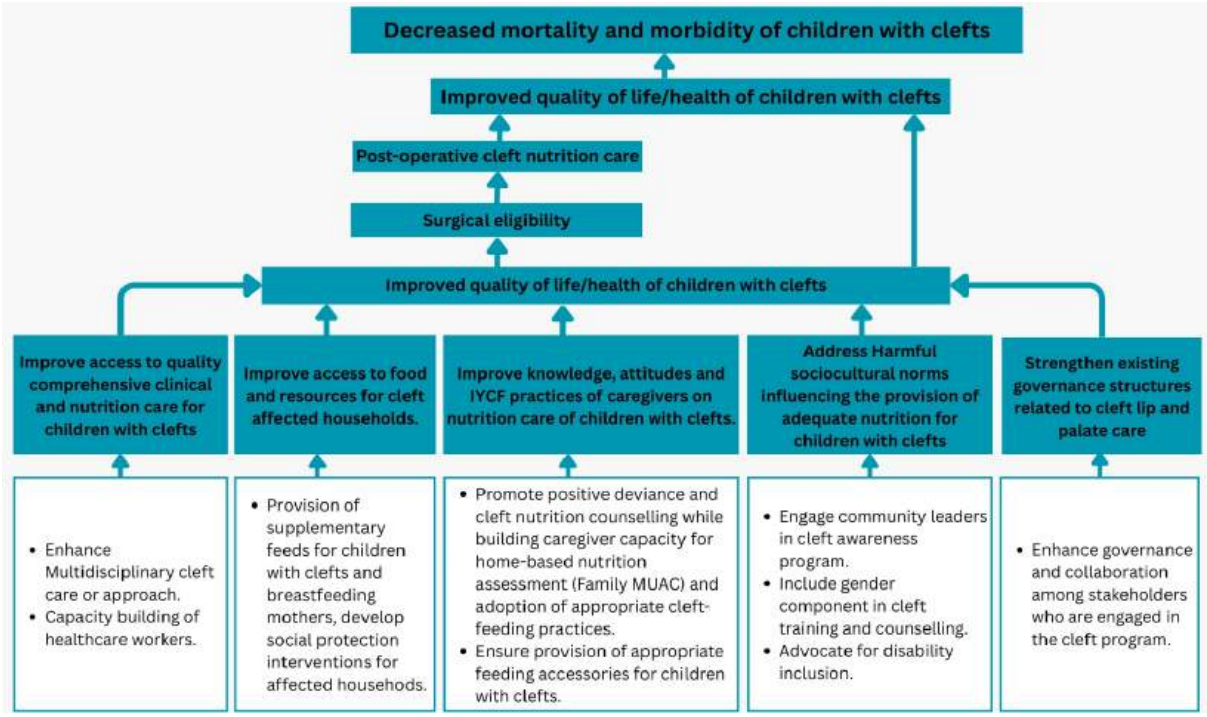

Figure 2: Theory of change to improve the nutritional status of children with clefts

Discussion

The study established that there are significant challenges being faced by children with cleft lip and palate (CL/P) and their caregivers in Zimbabwe, particularly concerning access to specialised nutritional care for children with clefts. With appropriate guidance and assistance, malnutrition is not a certainty for children with clefts. Every infant born with a cleft lip is capable of breastfeeding successfully, yet efforts to promote breastfeeding among mothers and

communities often overlook this aspect, leaving babies with clefts unprotected. A child with a cleft is primarily just a child. Neglecting to meet their fundamental human needs perpetuates health disparities (Kassebaum & Delage, 2022).

Effective coordination between organisations is required to ensure efficiency of services and improve equity (Akl et al., 2015). This study highlights the lack of effective coordination among multiple stakeholders and organizations involved in cleft care. The absence of collaboration has led to fragmented service delivery and the establishment of a disjointed national service for the management of cleft lip and palate (CL/P). Furthermore, there is a notable deficiency in a centralised monitoring system for patients with CL/P, which ultimately detracts from the health and nutrition of these vulnerable children.

Establishing a centralised database is essential for enhancing service delivery and ensuring that children receive continuous care from birth. The current lack of coordination also hinders the development of an appropriate referral system for cleft care, resulting in children arriving at healthcare facilities with pre-existing malnutrition. It is imperative to prioritise prevention over rehabilitation concerning malnutrition. According to UNICEF (2020), nutrition programs should operate under a fundamental principle which states that prevention of malnutrition is paramount in all contexts. In instances where prevention is unsuccessful, treatment becomes essential. Consequently, the primary objective of nutrition programs is to prevent child malnutrition in all its manifestations (UNICEF, 2024a). Despite the existence of effective rehabilitation methods, severe malnutrition is associated with decreased IQ, impaired cognitive function, lower academic performance, and an increase in behavioural issues (Schaetzel & Nyaku, 2015). Consequently, caregivers frequently navigate the healthcare system independently, seeking assistance from various cleft organisations, which can lead to missed opportunities for timely interventions and support.

Nutritional risk screening serves as an efficient and rapid initial tool for identifying patients at risk of malnutrition and should be conducted with precision and consistency (Reber Aubry et al., 2019). This study revealed that, during the cleft camp, the measurements taken for nutritional risk screening were not performed accurately, posing a significant risk for children with moderate or severe malnutrition who are scheduled for surgery. Additionally, it was observed that nutritional status assessments during the cleft camp relied on a single measurement. However, it is imperative to note that a reliable evaluation of nutritional status cannot be adequately derived from a solitary measurement. A child may exhibit weight and

length/height ratios that are appropriate for their age; nevertheless, a singular measurement fails to indicate whether their growth is stagnating or progressing as it provides merely a snapshot of their overall health. Continuous growth monitoring is essential for safeguarding children's health and development. Systematically tracking key growth indicators such as height, weight, and body mass index (BMI) — enables healthcare providers to detect deviations from typical growth patterns effectively (Al-Jawaldeh, 2024).

This study further revealed that healthcare workers lack adequate knowledge regarding cleft identification and management, as well as feeding techniques for caregivers. This knowledge deficit can hinder effective communication between healthcare providers and families, exacerbating the challenges of feeding and nutrition. Similarly, a study that was done by Huang *et al.* (2023) states that the inadequate feeding instructions from the healthcare workers are not only a source of frustration for the caregivers, but also impact the overall health of infants with clefts. They also found that none of the staff were trained on specialised feeding for children with clefts (Huang et al., 2023). This research also showed that healthcare professionals suggested that mothers purchase feeding bottles, despite the WHO's recommendation for cup feeding. Cup feeding serves as a secure alternative for feeding term, preterm, and infants with cleft lip or palate, eliminating the risk of nipple confusion until they are strong and fully capable of breastfeeding (WHO, 2018). Cleaning bottles can be a more arduous task than washing cups, as their design often harbours hard-to-reach crevices that can trap residue. This challenge significantly elevates the risk of contracting gastrointestinal issues, such as diarrhoea, and other infectious diseases for children. This threat is particularly pronounced in areas where access to clean and safe water is scarce.

Our research indicates that a substantial proportion of caregivers did not receive adequate counselling and nutritional education regarding the appropriate feeding practices for children born with a cleft. This observation aligns with findings reported by Delage et al. (2021), which emphasised that newborns with clefts across Africa face significant challenges due to insufficient access to timely feeding support. Furthermore, the study noted that, in cases of isolated cleft palate, there was often a lack of thorough palate examination at birth. This issue corroborates our findings and highlights a critical delay in early diagnosis, which subsequently postpones necessary feeding interventions and timely management. Such delays have a detrimental impact on the outcomes for these infants (Kassebaum & Delage, 2022). The study highlights that a lack of counselling and nutritional education for mothers of children with

clefts results in poor feeding practices. This undermines the Global Strategy for Infant and Young Child Feeding (IYCF) recommendations (UNICEF & WHO, 2003).

The findings of this study revealed a significant scarcity of resources within households affected by clefts, which leads to insufficient access to nutritious food and impedes the availability of quality healthcare services. Kanmodi et al. (2024) have also indicated that the higher incidence of cleft-related fatalities in Africa, in comparison to other regions, may be attributed to elevated levels of poverty and substandard healthcare (Kanmodi et al., 2024). Additionally, this study identified that stigma associated with cleft conditions adversely affects the nutritional care of children impacted by such conditions. Consequently, there is a pressing need for community engagement and educational initiatives to cultivate a supportive environment that promotes appropriate feeding practices and fosters greater acceptance of children with clefts.

The findings also underscore the urgent need for a cohesive approach to enhance nutritional care for children with CL/P in Zimbabwe. Developing a robust national nutrition program that integrates education, community support, and improved healthcare access can significantly impact the health outcomes of these children. Collaborative efforts among stakeholders, including government entities, healthcare providers, and community organisations, would be crucial in preventing malnutrition and facilitating timely cleft surgeries, ultimately improving the quality of life for affected children and their families. Lastly, the findings were used to establish a structured nutrition programme at Sally Mugabe Children's Hospital in partnership with Global Cleft and Craniofacial Organisation and Shumiro Trust, to effectively manage malnutrition among children with clefts. The patient's care pathway is shown in Figure 3.

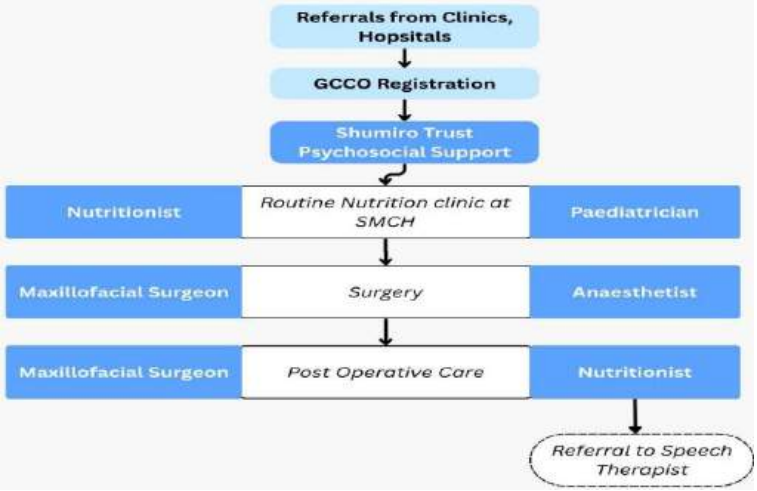

Figure 3: Patient care pathway for children with clefts in Harare

Conclusion

In conclusion, this research established that caregivers in Harare, Zimbabwe, faced multiple challenges in achieving optimal nutrition care for their children with clefts. At the individual level, the primary challenges were the lack of knowledge among caregivers regarding proper feeding practices for children with clefts and the high emotional stress experienced by mothers, which was often exacerbated by stigmatisation. At the community level, challenges included high rates of food insecurity and poverty, minimal support from husbands and family, and the negative impact of socio-cultural norms, such as stigmatisation and discrimination. At the health systems level, the critical issues were the scarcity of specialised nutritional services, inadequate training of healthcare professionals in cleft-specific feeding practices, a lack of collaboration leading to fragmented services, and a poorly developed referral system.

These multifaceted obstacles contribute to the high prevalence of malnutrition among children with cleft lip and palate (CL/P) in Zimbabwe. The findings underscore the urgent need for a cohesive and multi-level approach to enhance nutritional care, beginning with training healthcare professionals in best practices for infant and young child feeding in the context of cleft. Implementing the developed theory of change is essential to establish a robust, national nutrition program and improve the long-term health outcomes for this vulnerable paediatric population.

Recommendations

- Ministry of Health and Child Care to advocate for collaboration and standard of operation for organisations working on the cleft program.
- Engaging community leaders and the Ministry of Education in conducting cleft awareness campaigns in communities.
- Creating support groups for caregivers of children with clefts.
- Training health care workers on best Infant and Young Child Feeding (IYCF) practices for children with clefts.
- Incorporating cleft education in pre-service training of healthcare professionals in Zimbabwe.

Limitations of the study

The results cannot be generalisable for the whole population as the study focused on those participants who were able to access cleft services in selected institutions in Harare, Zimbabwe.

Key messages

i) It is imperative to acknowledge that the principles of Infant and Young Child Feeding (IYCF) apply to all children, including those diagnosed with clefts. While the presence of a cleft may necessitate modifications in feeding practices, it does not alter the nutritional requirements of the child.

ii) The World Health Organization (WHO) advocates for cup feeding as an effective approach for infants experiencing difficulties with breastfeeding. In comparison to bottles, cups are easier to clean and contribute to the preservation of breastmilk production.

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References

Adams, S., Mahieu, A., Verreijdt, P. M., Isaacs, S., & Breugem, C. C. (2025). Undernutrition in cleft palate surgery: effects on postoperative fistula formation in a tertiary children's hospital in southern Africa. *Journal of Craniofacial Surgery*, *36*(2), e198. https://doi.org/10.1097/SCS.0000000000010935

Akl, E. A., El-Jardali, F., Bou Karroum, L., El-Eid, J., Brax, H., Akik, C., Osman, M., Hassan, G., Itani, M., Farha, A., Pottie, K., & Oliver, S. (2015). Effectiveness of mechanisms and models of coordination between organizations, agencies and bodies providing or financing health services in humanitarian crises: A systematic review. *PloS One*, *10*(9), e0137159. https://doi.org/10.1371/journal.pone.0137159

Al-Jawaldeh, A. (2024). *Leila Cheikh Ismail, PHD, Associate professor, Department of Clinical Nutrition and Dietetics, College of Health Sciences,* University of Sharjah, Sharjah, UAE.

Conway, J. C., Taub, P. J., Kling, R., Oberoi, K., Doucette, J., & Jabs, E. W. (2015). Ten-year experience of more than 35,000 orofacial clefts in Africa. *BMC Pediatrics*, *15*(1), 8. https://doi.org/10.1186/s12887-015-0328-5

Delage, B., Kasengi, J., & Loanie, D. (2024, November 13). *Feeding hope: The crucial role of nutrition in cleft care | ENN*. https://www.ennonline.net/fex/74/en/feeding-hope-crucial-role-nutrition-cleft-care

Delage, B., Stieber, E., & Sheeran, P. (2022). Prevalence of malnutrition among children at primary cleft surgery: A cross-sectional analysis of a global database. *Journal of Global Health*, *12*, 04012. https://doi.org/10.7189/jogh.12.04012

Duarte, G. A., Ramos, R. B., & Cardoso, M. C. de A. F. (2016). Feeding methods for children with cleft lip and/or palate: A systematic review. *Brazilian Journal of Otorhinolaryngology*, *82*(5), 602–609. https://doi.org/10.1016/j.bjorl.2015.10.020

Escher, P. J., Zavala, H., Lee, D., Roby, B. B., & Chinnadurai, S. (2021). Malnutrition as a risk factor in cleft lip and palate surgery. *The Laryngoscope*, *131*(6), E2060–E2065. https://doi.org/10.1002/lary.29209

Huang, C., Green, K., Bland, L. E., & Fisher, J. D. (2023). Caregiver experiences of feeding instruction for infants born with cleft lip and/or palate. *The Internet Journal of Allied Health Sciences and Practice*. https://doi.org/10.46743/1540-580X/2023.2365

Kanmodi, K. K., Atteya, S. M., Elwan, A. H., Adewole, I., Akinsolu, F. T., Abodunrin, O. R., Olagunju, M. T., Nwafor, J. N., Aly, N. M., Salami, A. A., Foláyan, M. O., & El Tantawi, M. (2024). Nutrition and diet in children with orofacial clefts in Africa: A scoping review. *BMC Oral Health*, *24*, 1341. https://doi.org/10.1186/s12903-024-05130-8

Kassebaum, N. J., & Delage, B. (2022). *Produced by the Institute for Health Metrics and Evaluation and Smile Train*.

MOHCC. (2021). *Ministry, Smile Train, expand free cleft lip and cleft palate patients' identification and treatment programme.* https://www.facebook.com/ photo.php? fbid=3872911216145710&id=148565931913609&set=a.163377183765817

Olofin, I., McDonald, C. M., Ezzati, M., Flaxman, S., Black, R. E., Fawzi, W. W., Caulfield, L. E., Danaei, G., & Nutrition Impact Model Study (anthropometry cohort pooling). (2013). Associations of suboptimal growth with all-cause and cause-specific mortality in children under five years: A pooled analysis of ten prospective studies. *PloS One*, *8*(5), e64636. https://doi.org/10.1371/journal.pone.0064636

Reber Aubry, E., Gomes, F., Vasiloglou, M., Schuetz, P., & Stanga, Z. (2019). Nutritional risk screening and assessment. *Journal of Clinical Medicine*, *8*, 1065. https://doi.org/10.3390/jcm8071065

Schaetzel, T., & Nyaku, A. (2015). *The case for preventing malnutrition through improved infant feeding and management of childhood illness*.

Smile train. (2018). *Supporting comprehensive cleft care through nutrition and feeding*. https://www.smiletrain.org/sites/default/files/2021-01/nutrition-feeding-trainer-manual.pdf

UNICEF. (2024a). *UNICEF proven solutions SDGs 22092024.pdf*. https://www.unicef.org/media/162436/file/UNICEF%20Proven%20solutions%20SDGs%2022092024.pdf.pdf

UNICEF. (2024b). *Zimbabwe livelihoods assessment report 2024 | UNICEF Zimbabwe*. https://www.unicef.org/zimbabwe/reports/zimbabwe-livelihoods-assessment-report-2024

UNICEF, & WHO. (2003). *Global Strategy for Infant and Young Child Feeding*. World Health Organization.

WHO. (2018). *Directorate of Nursing Affairs*. https://platform.who.int/docs/default-source/mca-documents/policy-documents/operational-guidance/OMN-MN-62-03-OPERATIONALGUIDANCE-eng-Neonatal-Nursing-Procedures-Cup-Feeding.pdf.