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Biopsychosocial Impact of Lymphaticovenous Malformations on Children and Their Parents: Emphasizing a Multidisciplinary Approach

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Abstract

Introduction: Lymphaticovenous malformations (LVM) are benign congenital anomalies of the venous and lymphatic systems, frequently presenting as complex masses in the head and neck region of children. While the clinical features of LVM are well-documented, there is a lack of comprehensive studies addressing their holistic impact on affected children and their families. **Objectives:** This qualitative study explores the physical, psychological, and social challenges faced by children with head and neck LVM and the emotional and financial burdens experienced by their parents. It also evaluates the effectiveness of a multidisciplinary approach in managing these challenges. **Methods:** Over seven months, data were collected through monthly multidisciplinary team (MDT) clinics, bi-monthly tele-clinics, and continuous email communication. The MDT included interventional radiologists, surgeons, psychologists, physiotherapists, nurse specialists, and administrative staff. Additional specialists were consulted as needed. The study focused on children's physical symptoms (appearance concerns, pain, infections, bleeding, heaviness, tongue involvement), psychological and social issues (bullying, self-esteem, social isolation, school absenteeism), and parental concerns. Management strategies and their outcomes were also documented. **Results:** Children with LVM experienced significant distress due to visible deformities, chronic pain, and recurrent infections, leading to social isolation, bullying, and low self-esteem. Parents reported constant stress over their child's well-being, concerns about social interactions, and financial strain from taking time off work for care and medical appointments. Interventions—including surgical procedures and interventional radiology treatments like sclerotherapy, counseling, laser treatments, and camouflage techniques—resulted in reported improvements across physical, psychological, and social domains. **Conclusions:** LVM significantly

impacts the biopsychosocial well-being of both children and their parents. A multidisciplinary approach is essential for effective management, addressing not only the medical but also the psychological and social needs of affected families. Future studies with larger, multi-center cohorts are recommended to further validate these findings and explore new therapeutic strategies.

Keywords

Lymphaticovenous Malformations, Multidisciplinary Care, Psychosocial Impact

1. Introduction

Lymphaticovenous malformations (LVM) are benign congenital anomalies of the venous and lymphatic systems [1]. These malformations are part of a broader category of vascular anomalies, which are classified by the International Society for the Study of Vascular Anomalies (ISSVA) into vascular tumours and vascular malformations. Occurring during the development of the vascular system, they are generally present at birth and grow with the child but are often unnoticed until symptoms manifest. According to the literature, their incidence in children is estimated to be 6% across all benign tumors, with 60% presenting as complex masses in the head and neck region [1] [2].

These malformations can be exacerbated by trauma, infection, and hormonal changes, leading to severe functional and aesthetic impairments that profoundly affect the quality of life of affected individuals [2]. Despite well-documented symptomatology and presentation, there remains a gap in comprehensive studies that address the holistic impact of LVM on both children and their families.

The primary objective of this study is to explore the impact of LVM on children and their parents from symptomatic, physical, psychological, and social perspectives. Additionally, it aims to provide insights into the emotional and financial burdens faced by parents. Ultimately, this study seeks to understand these challenges while highlighting the importance of a comprehensive, multidisciplinary approach to management.

2. Methods

This study employed a qualitative design to explore the impact of lymphaticovenous malformations (LVM) within the head and neck region on children and their parents. Data collection included in-clinic evaluations during multidisciplinary team (MDT) clinics, held three times per month over seven months, with an average of seven patients seen per clinic. Additionally, structured follow-up data was gathered bi-monthly through tele-clinics, and further insights were collected through continuous email communication over a one-year period. This open communication channel allowed parents to reach out with concerns regarding acute episodes and the management of LVM-related issues; on

average, four emails were received per week, with approximately 25% of these addressing socio-psychological impacts. Data from emails was systematically categorized by concern type and reviewed for recurring themes, ensuring reliability. All collected data were anonymized and securely stored in accordance with hospital guidelines.

The multidisciplinary team comprised various specialists, each contributing specific expertise essential to a comprehensive care approach:

- Interventional Radiology: Responsible for radiological diagnoses, sclerotherapy, embolization, and guided biopsies to manage LVM.
- Plastic Surgery: Conducts clinical examinations and assessments, performs surgical excisions when indicated, manages complications, and provides LASER treatment as appropriate.
- Psychology Team: Offers support to both children and parents, addressing the emotional and psychological impacts associated with LVM.
- Genetics: Identifies genetic backgrounds, advises on genetic testing, and recommends specific genetic panels based on family history and phenotype.
- Oncology: Oversees medical management in cases where findings from genetic testing indicate an oncological approach.
- Additional Specialties: These include ENT, orthopedics, gynecology, general surgery, ophthalmology, and pharmacy, which join the MDT as needed to address unique clinical concerns.

Data collection targeted children's physical concerns (appearance, pain, infections, bleeding, heaviness, tongue involvement), psychological concerns (bullying, self-esteem, social isolation), and social concerns (school absenteeism, participation in physical activities, quality of life); relevant parental concerns were also documented. Management strategies were also recorded and correlated with the aforementioned concerns.

Children were excluded from the study if they had vascular anomalies not classified as lymphatic malformations or combined lymphaticovenous malformations (LVM) according to the International Society for the Study of Vascular Anomalies (ISSVA) classification. In this classification:

- Vascular Malformations are divided by vessel type: lymphatic, venous, arteriovenous, and capillary malformations. Lymphatic malformations (LM) and combined lymphatic anomalies, such as LVM, were the study's primary focus.
- Vascular Tumors, which include lesions with cell proliferation such as hemangiomas, were excluded as they do not align with the structural nature of vascular malformations.
- Additionally, complex combined malformations—those involving multiple types of vessels—were eligible for inclusion only if lymphatic involvement was identified, as in lymphaticovenous malformations (LVM).

Other exclusions applied if data available included only information unrelated to the impact of LVM on children and their parents, if families did not consent to participate, or if they were not involved in MDT clinics or tele-clinics.

3. Results

The qualitative analysis of the impact of LVM on children and their parents revealed significant physical, psychological, and social challenges as shown below.

3.1. Impact on the Child

From a physical point of view, the most reported concern was the appearance of the malformations, which often led to distress and impacted the child's self-esteem. Chronic pain, Recurrent oozing, and infections were also common, often exacerbated by infections or minor physical trauma. Heaviness of the malformations sometimes led to discomfort and difficulty in physical activities. In cases where the tongue was involved as seen in Figure 1, children experienced a metallic taste and difficulties in eating.

Figure 1. Child's tongue with a significant lymphaticovenous malformation, leading to visible enlargement and texture irregularities. This physical manifestation contributed to notable psychosocial challenges, as reported by the child. Peers at school often commented on the appearance, saying "it does not look normal." The child expressed feeling more comfortable during the COVID-19 pandemic when mask-wearing was prevalent, as it provided a way to cover the malformation.

Following with the psychological and social challenges most children faced bullying and negative social reactions due to their appearance, leading to significant stress and worrying. Often, this was reported alongside social isolation and low self-esteem. The visibility of the malformations further compounded these issues, as children were frequently subjected to staring and unwanted attention. School absenteeism was another major consequence, driven by both physical and psychological factors.

3.2. Impact on Parents

Parents of children with LVM also faced significant emotional and psychological challenges. The most reported one was the worry about their child's appearance and the potential for bullying, which resulted a constant source of stress to the parents. Parents also reported concerns regarding their child's social interactions because of LVM. Finally, parents also mentioned having to take time off work

constantly to care for their children and attend medical appointments, leading to loss of income which adds to the stress toll.

3.3. Management Strategies

As a consequence of such concerns, some children underwent surgical procedures to manage the malformations. These surgeries aimed to reduce the size and symptoms of the malformations but were not always curative. Interventional radiology, including procedures like sclerotherapy, was used to address the vascular components of the malformations. From a non-invasive point of view children underwent counselling and support groups, to help them cope with the emotional and psychological impacts of LVM. Laser treatments were also used to manage the appearance and symptoms of the malformations. Finally, camouflage techniques were employed to improve the children's self-esteem and reduce social stigma. All the patients and parents reported improvements across all domains following such interventions.

4. Discussion

This study aimed to explore the multifaceted impact of lymphaticovenous malformations (LVM). The findings highlight significant physical, psychological, and social challenges experienced by the affected children and their families, each of these will be discussed in turn with reference to the literature.

4.1. Impact on the Child

From a physical point of view symptoms such as pain, recurrent infections, and the visibility of malformations, align with existing literature on the subject. LVMs often lead to chronic pain and recurrent infections, which significantly affect the quality of life of affected individuals [1] [3]. The visibility of these malformations also causes distress, as noted by authors who reported that the aesthetic impact of LVMs can lead to considerable psychological strain [2] [4].

The psychological and social issues highlighted in the study are in line with other research which studied the effect of other visible chronic health conditions in children [4] [5]. A meta-analysis that evaluated the reasons behind bullying found that children with visible craniofacial malformation are at the highest risk of victimization [5]. Although, the reasons for this were not completely clear they hypothesize that it might be related to not meeting the beauty standards of other peers, as facial appearances are highly impactful in social interactions [5]. Social isolation and low self-esteem are also prevalent, emphasizing the need for psychological support in managing these conditions [4].

4.2. Impact on Parents

Our results suggest that parents of children with LVM face significant emotional and financial burdens. Parental financial difficulties due to time off work are a common theme in the literature, especially in those who have children with

chronic health conditions [4] [5]. This difficulty is further compounded by a constant worry regarding their child's current and future wellbeing, which highlights the importance of providing care for both parents and children [4] [5].

4.3. Multidisciplinary Approach

The effectiveness of the multidisciplinary team (MDT) approach is well-documented in existing research, which demonstrates improved patient outcomes with minimal complications in the management of conditions like abdominal lymphatic malformations [6] [7]. MDTs are crucial in managing rare conditions because they offer comprehensive care that addresses both medical and psychosocial needs [6]. This holistic approach has proven particularly beneficial in managing lymphaticovenous malformations (LVM), as highlighted throughout this paper. The coordinated efforts of surgeons, psychologists, and other specialists ensure that all aspects of the condition are managed effectively.

4.3. Limitations and Future Research

The main challenge faced by this study was maintaining consistent follow up periods across all patients. This tends to be a common issue within qualitative research papers evaluating chronic conditions. Additionally, the small sample size within the context of a single centre limits the generalizability of the findings. In the future studies should assess a larger variety of patients across different centres. Additionally, they could focus on exploring management specific outcomes of newer therapeutic approaches for LVM. Finally, the study did not employ a validated scale to quantitatively measure the psychological impact on children. It is recommended that psychological assessment scales be introduced in clinical settings.

Although there are limitations to the generalizability of the results, these still have some practical implications. An MDT approach may need to be adopted when managing LVM to ensure holistic care of physical and psychosocial needs is provided. As shown throughout this paper, these conditions can have a significant toll on both parents and children's wellbeing. Hence, empathy and effective communication are key when helping families navigate management options associated with LVM.

5. Conclusion

This study highlights the importance of a multidisciplinary approach when managing LVM, a condition which has a significant impact biopsychosocially in both patients and parents alike. The findings align with the scarce literature available and provide a basis for future care recommendations.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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