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PARENTAL EXPERIENCE OF PRENATAL DIAGNOSIS OF LYMPHATIC MALFORMATION

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ABSTRACT

Lymphatic malformations (LM) are a developmental anomaly arising from a somatic mutation in the lymphatic endothelial cells. This study investigated parental experiences associated with prenatal diagnosis of LM. Parents of 5 children diagnosed prenatally with LM were recruited from the Vascular Anomalies Clinic at the Royal Children's Hospital, Melbourne. Ten in-depth semi-structured interviews were conducted with each parent separately to explore their experiences and views at the time of diagnosis and immediately after childbirth. Transcribed interviews were coded and thematically analyzed. Parents experienced prenatal diagnosis of LM as an unexpected and traumatic event. The lack of adequate information and clear care pathway created confusion and added to the difficulty of understanding the impact of LM on the unborn child and what to expect after the child was born. Parents used the internet as the primary source of additional information; however, some parents found that information distressing. Differences between mothers and fathers were noted in terms of roles that each parent played and their emotional responses during pregnancy and the prenatal diagnosis. Closer connection between obstetric centers and specialized treatment clinics are suggested to facilitate better understanding of the LM impact on the unborn child and available treatment options after birth.

Keywords: lymphatic malformation, parental experience, prenatal diagnosis

Lymphatic malformations (LMs) are a slow-flow human vascular anomaly characterized by a localized overgrowth of functionally impaired lymphatic endothelial cell-lined cystic structures (1,2). It is estimated that the LM prevalence is 30 per 100,000 births (3). The cause of LMs has been proposed to be single point somatic mutations in the *PIK3CA* gene that regulates cell growth, cell division and metabolism (4). LMs are mostly sporadic but can present as a component of CLOVES (congenital lipomatous overgrowth vascular malformation epidermal nevi and scoliosis/skeletal/spinal abnormalities) (5) and Proteus syndromes (6). Although the term "cystic hygroma" has been applied to this condition in the past, LM must be differentiated from frequently transitory fetal fluid collections in the nuchal areas which are associated with some aneuploidies (7).

Depending on their location and size, LMs can cause feeding difficulties, airway obstruction, chronic and major deformity (8). Hemorrhage into the cystic spaces and thrombosis cause pain, disability and occasionally respiratory obstruction (9).

Effective treatments are available, but treatment plans are often complex and some children require repeated interventions over many years.

LMs are generally diagnosed in the second and third trimester by prenatal ultrasound (10), allowing for specific birthing plans and pre-natal and post-natal medical care to be provided (11,12). These LMs are predominately large macrocystic lesions located in the head and neck region (13) and remain visible throughout the pregnancy (14). In the Eurofetus study of babies with ultrasound abnormalities, approximately 97% LMs were correctly diagnosed prenatally (15). While ultrasound examinations have been used in obstetrics since the 1970's (16), the general public seems mostly unaware that the purpose of the second trimester ultrasound is to screen for fetal abnormalities (17-19). Consequently, receiving a prenatal diagnosis may be experienced as an unexpected traumatic event, characterized by intense distress, helplessness and emotions such as anger, and disruption of basic values and beliefs (20,21). The aim of our study was to explore parental experiences following prenatal diagnosis of LMs. We sought to explore parental experiences during the period from receiving a first abnormal prenatal ultrasound to diagnosis, subsequent interactions with the healthcare providers and what they felt with regards to information on LMs provided to them at the time of diagnosis. We also asked parents if they felt we can improve current clinical practice and what clinicians could do to ease the experience of parents during this time.

METHODS

Parents were recruited from the Vascular Anomalies Clinic at the Royal Children's Hospital, Melbourne. The selection criteria were parents who received a prenatal diagnosis of LM in the last 10 years and parents who are fluent in English. In total, six families registered interest to participate in the study. Investigation of a range of experiences was achieved through semi-structured interviews (22,23). The interviews were conducted between June and August 2015 in a quiet room, or, if the parents requested it, by telephone. Open-ended questions were used as prompts to ensure certain topics about the parents' experiences were explored. One-on-one interviews allowed exploration of the differences between the maternal and paternal experience. All interviews were audio-recorded and transcribed verbatim and pseudonyms assigned.

Transcribed interviews underwent thematic analysis (24) to identify emerging themes. The data were entered into NVivo data management software (version 10, QSR International Pty Ltd, Melbourne, Australia). All transcripts were coded by the interviewer (LH) and co-coded by another member of the research team. To ensure consistency and rigor in analysis, codes and themes derived from the data were discussed within the research group to reach a consensus of the analysis and interpretation of the data (24). The study was approved by the RCH Human Research Ethics Committee (HREC 35073 A).

RESULTS

Five mothers and five fathers were interviewed separately, representing 5 families. A sixth family expressed interest, but did not participate as a suitable interview time could not be arranged. Four interviews were conducted face-to-face and 6 interviews were conducted by telephone. Interviews ranged from 45-85 minutes, the average time being 60 minutes. Demographic characteristics of the parents are presented in *Table 1.*

Through these interviews, six major themes emerged: 1) feelings of shock and anxiety once the initial ultrasound findings and the diagnosis were given, 2) feeling the inadequacy of information provided at the time of diagnosis and during pregnancy, 3) feeling a great need for more information about LMs than provided by the specialists, 4) mixed emotions when preparing for the

TABLE 1
Demographic Characteristics of the Parents

Participant	Child (Gender)	Extended family in Australia	First pregnancy	First abnormal ultrasound	Prenatal LM diagnosis	Birth	Baby trans-ferred[1]	NICU	Number of hospitals referred to[2]	Age of first discharge[3]	Age of first treatment[4]	Current treatment status
Sarah	Jack (Male)	No	Yes	20 weeks gestation	26 weeks gestation	Planed EXIT Procedure	Yes	Yes, baby intubated	2	8 weeks	7 days	In progress
Chris		No										
Tamara	Alex (Male)	Yes	Yes	20 weeks gestation	22 weeks gestation	Premature labor at 34 weeks, emergency C-section	No	Yes, baby monitored as pre-mature	3	2 weeks	3 weeks	Regular reviews in outpatient clinic
George		No	Previous miscarriages									
Ellie	Douglas (Male)	No	Yes	12 weeks gestation	12 weeks gestation, confirmed at birth	Emergency C-section	No	No	2	5 days	6 weeks	Regular reviews in outpatient clinic
Rob		Yes										
Jenny	Amy (Female)	Yes	Yes	20 weeks gestation	26 weeks gestation	Planned C-section	Yes	Yes, baby intubated	4	5 days	7 weeks	In progress
Dave		Yes										
Melissa	Lilly (Female)	No	Yes	28 weeks gestation	28 weeks gestation	Planned C-section	No	No	3	5 days	Waiting for treatment to begin	Waiting for treatment to begin
Jason		Yes										

[1]Baby transferred to another hospital for after-birth for LM management; [2]Number of hospitals referred to for pre-natal and post-natal care for LM; [3]Age of child first discharged from the hospital due to LM; [4]Age of first surgery or sclerotherapy treatment of LM

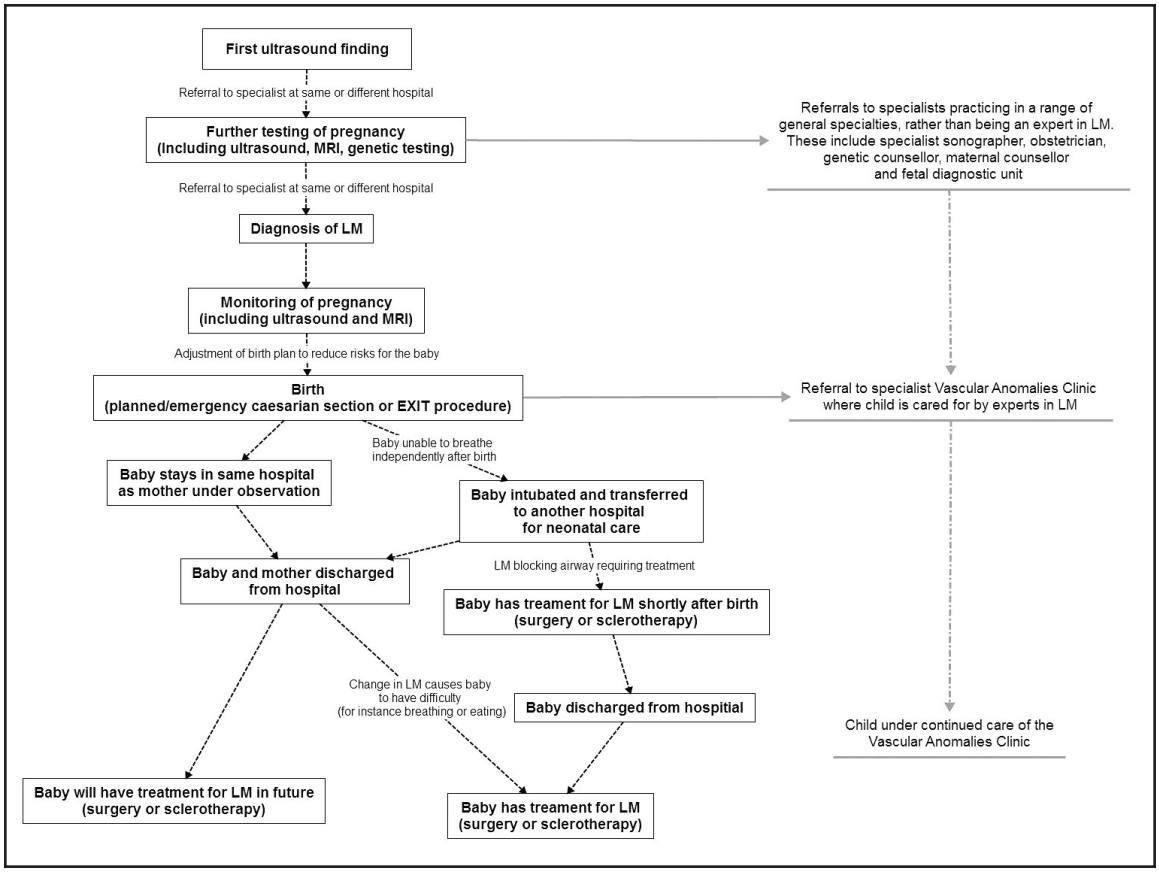

Fig. 1. Generalized care pathway experienced by parents following pre-natal diagnosis of lymphatic malformations

birth of a child with LM, 5) experiencing bonding with the child after birth, and 6) feeling that clinicians (medical, nursing, genetic counseling) need to improve their communication during this time and develop better general care pathway from prenatal diagnosis to post-natal care. Parental understanding of the general care pathway plan presented to them after ultrasound diagnosis, as described in the interviews, is summarized in *Fig. 1*. Representative quotations are presented as evidence. Where text was truncated, five full stops are used (.....); however, truncation of the results did not change the meaning of the results. English was the second language for three parents leading to slight language anomalies in some quotations. At the time of interview, parents' children were between 4 months and 2 years old.

Feelings of shock and anxiety to initial ultrasound findings and the diagnosis

At the time of first abnormal ultrasound, parents described feeling shock followed by great anxiety for the wellbeing of their unborn child. While some parents reported seeing a specialist within days, two parents reported waiting 6 weeks for an appointment:

George: *They told us the sort of bad news they've found something. They weren't too sort of sure what it was..... of course at this stage we're thinking the worst, I guess the mind sort of starts racing.*

This anxiety was compounded by the

presence of multiple doctors in the room during the ultrasound:

> **Tamara:** *Every ultrasound there were lots of people calling to look..... this is obviously something really rare that people don't get to see..... the guy says 'um you do realize there's a big lump on your baby's neck don't you?' Like yeah, that's why we're here.*

Throughout the entire experience, fathers felt that they had to be positive, even if they thought that the outcome may not be positive, and support their partners to the best of their ability. The differences in maternal and paternal experiences are summarized in *Fig. 2*.

Feeling the inadequacy of information provided at the time of diagnosis and during pregnancy

At the time of diagnosis, parents received variable information about LMs. Many parents felt that the healthcare workers knew very little about LMs, which added to their anxiety and frustration. Some parents consulted several specialists before getting accurate information about what the finding meant. Ellie and Rob found out that their son Douglas had a cyst at their first trimester ultrasound and wondered if the healthcare team did not know the information or were withholding it from them:

> **Ellie:** *The radiologist, we just thought didn't seem to know too much about it and neither did our obstetrician….. It seemed like they kept it all very, like they try to keep a lot of information from us, instead of try and give us information..... [Obstetrician] would just kind of push us along and it would be really hard. Like we'd ask him questions and he would..... not really ignore them but not really answer them.....*

Both parents reported feeling responsible and asked themselves why this has happened to their child and what they did to contribute to their child's condition. Melissa wondered if it was caused by something she had done while pregnant:

> **Melissa:** *I was crying a lot that day.....I couldn't sleep, I was thinking why is this happening to my baby..... And I was thinking what have I done wrong because I was fine the whole pregnancy..... I was talking to the doctor..... he said to me… there is no explanation why this thing happens, it just happens.....*

Parents spoke of the relief at knowing what condition their child had, allowing parents to find more information about how LMs might affect their child and learning of available treatments:

> **Dave:** *We didn't know what we were dealing with so having an actual answer of what it was, was a relief in itself..... it was in that knowledge of what it was and what was needed.....*

At birth, one of the possible complications of LMs is that the airway obstruction may require intubation. Two babies did not have any complications and stayed with their mother in hospital under observation. One baby was monitored due to prematurity. Two babies required intubation and were transferred to another hospital for advanced care directly or soon after birth. Their parents spoke of the stress and anxiety of being separated from their baby when transferred to another hospital for treatment.

Feeling a need for additional information on cause, diagnosis, and treatment of LMs

At the time of diagnosis, healthcare workers predominantly advised parents not to search for LM-related information on the internet. However, parents reported that they felt they had to know all that there is to know on the LMs and they satisfied that need by resorting to the internet after clinical appointments:

> **Jenny:** ..... *I was googling before I even got to my car..... On the report that they gave me it said cystic hygroma, so that's what I was googling..... So when I was*

Mother's experience		Father's experience	
Unable to help child	You know, when you see him and it's 'oh my god poor baby' and the worst part you know, what is it for me….. is like, I want to do for him a lot of things, but I can't, I can't do anything. **(Sarah)**	**Dealing with emotion**	I think all of the men are emotional but they don't want show….. I don't want show anyone that I'm very emotional or I'm very upset….. I'm not happy with Jacks neck. Every time when I look at….. his neck, it make me very upset. **(Chris)**
Trying to be positive	Jason, he's more maybe, not emotional but….. he feels more what you know what's happening with Lilly. Yeah, so I'm trying to be positive. **(Melissa)**	**Wanting to 'fix' the situation**	It makes you upset cause you can't do nothing about it….. it's something that you just can't obviously you can't fix that at all. **(Jason)**
Partner felt he had to be strong for me	He probably felt more helpless than I did and he sort had to carry on, because I was so sick from the pregnancy….. He had to carry on working and that sort of thing and being….. the man, I think he felt like he had to be strong for me. **(Tamara)**	**The only thing you can do is support your wife**	You feel not very useful a lot of the time. I guess, cause, I guess just as it is with pregnancy, it's a very, its quite a personal thing….. for the Mum….. So you just end up just trying to support your wife I guess. You know keep the, a shoulder to cry on kind of thing….. cause she's worried about the baby, you worry about your wife. **(George)**
On a different wavelength	I think Dave was a little bit in denial at the beginning. He was like everything will be fine, you're being very negative, you have to be very positive. So we were kind of on a different wavelength at the beginning. **(Jenny)**	**Trying to stay strong**	Just try and reassure her that everything was going to be ok but deep down I didn't know whether everything was going to be ok. I was just trying to be strong for her so she didn't fall apart….. Trying to stay strong on the outside but you know, sort of falling apart on the inside. **(Dave)**
Different perception of child's condition	It's as if like, throughout the whole ride I was the only one who was really going thorough it….. We would talk about it and he would you know, be really supportive and everything, but then he'd be like oh don't worry, it's going to be fine….. Whereas, I like, I immediately decided it wasn't. **(Ellie)**	**Different coping mechanisms**	I was just giving her a lot of support. I didn't really need the support personally….. for me I was fine dealing with it. But anyone who's, I'll say normal, it would be quite a scary process. **(Rob)**

Fig. 2. Couple's experiences of their pregnancy and prenatal diagnosis.

looking up what that was, it was, oh, to be honest with you, I was thinking I'm not going to come home with the baby.

Most parents reported that examining online information was frustrating as they could not determine if information was relevant to their child, some deciding after an initial search not to look further. In contrast, Tamara and George found online information to be a valuable resource:

Tamara: *To be honest I felt it more reassuring looking on the internet because I found lots of survival stories and that sort of thing. Especially bearing in mind we were thinking the chance of the baby was going to die was pretty high.*

Some parents also spoke of difficult conversations both as a couple and with healthcare providers regarding termination of pregnancy:

Chris: *if this baby born with some problem in his neck or some problem that is not very nice, first of all it's very difficult for him, second for us….. I told my wife if you like, we can abort and she told me no, never. After that I thought with myself….. this one is a human and I won't say no, I don't want him. No.*

George and Tamara were the only parents who saw a genetic counselor [GC], which they described as the low point in their pregnancy. They felt the [GC] knew little about LMs, poorly understood the possible conditions affecting Alex and persistently presented termination of pregnancy as an option, even though it was not something George and Tamara would consider. Like Jenny, George and Tamara also wondered if they were going to lose their baby:

George: *The impression we got from [GC] was basically there's something wrong with your baby, consider aborting….. We're both [religion] so we wouldn't abort the baby anyway…. Something's going to happen with this baby and we're probably not going to have him.*

Dave and Jenny appreciated knowing there were other children with LMs who were successfully treated, making this seem possible for their daughter Amy:

Dave: *We had everything that we needed or wanted to know answered, they were fantastic like that….. You know, hearing from the doctors that we're going to deal with her once she was born, that they have dealt with it before and you know the success rate was right up there. So that was a big relief.*

Parents also spoke about wanting to meet other families and children who have LM at the time of diagnosis and in the present moment.

Jenny: *Hearing other people's personal experiences, the positives and the negatives, I think that would have been a fantastic, fantastic help. Or even some sort of support group or something like that…..*

Experiencing mixed emotions when preparing for the birth of a child with LM

Having a diagnosis did not necessarily mean parents understood what may lie ahead for their child or what to expect when the child was born. Parents spoke of trying to prepare themselves for their child's birth by learning about their child's condition during pregnancy:

Jenny: *I made sure that I went through every link on google to know exactly what it was we were dealing with. I kind of didn't want to go in and when she's born be shocked. It was very difficult to have a normal pregnancy.*

Sarah, as did other parents, spoke of seeing multiple doctors who all had different opinions on the survival prognosis and care pathway for Jack once he was born, which made it difficult for her to know what to expect:

Sarah: *One doctor will come to ultrasound scan, obstetricians will say 'you know he will [be] born, we'll do an operation, will take these things, will say then fine you go'..... After two weeks I*

am coming to [an]other doctor 'we don't know maybe he will not breathe and we can't help him'..... different doctors say different things.

Melissa described the trust she put in the health care system when she learnt of Lilly's condition and hope for the best possible outcome:

Melissa: ..... *[I] relaxed a little bit, because I knew that I would have good treatment and everything would be planned. And everything would be you know, done by step by step so she could be fine.*

However, like other parents, Melissa described that she found it difficult to comprehend what Lilly will look like once she was born:

Melissa: *They're talking and explaining but you don't have picture in your head how she will look.*

Experiencing bonding with the child after birth

The first time parents saw their child when they were born, the reality of the LM was often different to what the parents were expecting. Some parents found that the LM did not affect their child as much as they had imagined, while other parents spoke of the LM appearing larger than expected. For example, Ellie felt that the medical team understated Douglas' condition. She thought that Douglas would have a small cyst that could be easily removed after birth, while Rob hoped it would vanish naturally after Douglas was born:

Rob: *I sort of assumed that it would go away, that it was nothing to worry about. A lot of kids born with a lot of sort of, you know, weird things but then it just vanishes all of a sudden..... I had high hopes on that.*

Parents described bringing their baby home from hospital as a positive step to starting their life as a family. Some parents talked about feeling anxious caring for their child and unsure about the implications of their child's LM. Parents spoke at length about how other people reacted to their child and spoke of not wanting sympathy; rather, they wanted their child to be accepted like any other child.

Parents also reflected on their experiences of having a child who has LM, from the initial ultrasound finding to their current life with their child:

George: *From being told that he's got a serious condition and you should think about aborting him to where we are now, it's quite incredible really.*

Jenny: *To know how far that we've come already, it's just amazing..... Everything else just seems so distant, especially when you wake up in the morning and Amy's got the biggest smile on her face..... just makes everything, just so worth it.*

Feeling that clinicians need to improve their communication and develop a better general care pathway from prenatal diagnosis to post-natal care

Parents suggested that a printed or geographically relevant online information resource containing basic information on LM such as the cause of the condition, what to expect at birth and treatment options after birth should be provided to parents at the time of diagnosis:

George: *If early on, if we had had a leaflet that just spelt out information..... it would have just answered so many questions. And because it's from sort of a trusted source as well, that would be really valuable.*

Rob suggested that an information pack or website with case studies would be useful for parents, which would include:

Rob: *What to expect. So when he does come out, this is what he may look like, this is what may happen during the first few days, this is how best to sort of treat it. What you can do, sort of moving forward and the support programs.*

Rob suggested further training for medical professionals about LMs and the possible complications during birth and after birth was needed, especially as Ellie had an emergency cesarean section. They both have reservations about what may have happened to their child if Ellie had given birth naturally:

Rob: *I think a bit more training for the obstetrician, in terms of understanding that if a child has a cyst, natural birth is out of the question.*

Before their child was born, parents were unaware that specialized multidisciplinary vascular anomalies clinics existed where LM specialists could care for their child. Parents said that linking the vascular anomalies clinics specializing in treatment of LMs with the obstetrics services at the time of diagnosis would be useful for parents and improve the care pathway:

George: *At the (...) hospital there is a whole set up for children with these kinds of conditions and other similar conditions. We, looking back, we kind of think oh, there was that whole sort of resource there of knowledge and support, but we didn't know anything about it.*

DISCUSSION

All parents described the experience of the first ultrasound finding to the time of diagnosis as an unexpected and traumatic event, the stress of which was exacerbated by receiving conflicting advice from multiple healthcare professionals. This study has identified that parents would like to have more accurate information about LM, better understanding of how LM will affect their child after birth (including appearance), a clear post-natal care pathway, and earlier contact with vascular anomalies treatment specialists and other parents whose children have been diagnosed with LM.

Most parents turned to the internet for their unmet information needs, suggesting that it is futile for healthcare specialists to advise them otherwise. Parents suggested, however, that provision of pamphlets or web-based region-specific online information on LMs might have reduced their anxiety. The approach of providing written information in conjunction with oral counseling has been shown to be effective in other situations (25).

Parents reported concern at finding it difficult to imagine their child's appearance after birth. They felt that seeing photographs of children before and after surgery might help visualize what is possible for their child. Parents whose children are prenatally diagnosed with cleft lip and palate confirm this suggestion, describing feeling relieved seeing images of children before and after corrective surgery (26). However, the use of images prenatally poses problems as these same parents worried that their child would have the 'worst' sort of cleft shown to them in pictures. Cleft parents reported that they preferred to know the full spectrum of the condition, positives and negatives, to allow them to mentally prepare for the range of severity that may affect their child (26).

Some differences between the experience of mothers and fathers during pregnancy and prenatal diagnosis were evident. Fathers described being supportive and trying to reassure their partner that 'everything is going to be ok', without knowing if this was the case. Fathers mentioned containing their emotions, maintaining positivity and 'staying strong' for their partner. This is consistent with previous reports of fathers playing a protective and supportive role during the time of prenatal screening and diagnosis (27). Previous research suggested that fathers take on a role of the information gatherer (27,28). However, in this study, information gathering was mostly a shared experience or driven by the mother.

Parents suggested that a clear post-natal care pathway would have eased their anxiety. In the case of congenital heart disease, following prenatal diagnosis, parents are referred to an expert pediatric cardiologist who consults with parents and coordinates

care with the rest of their obstetrics team to provide unified advice to parents about the best care for their child. Such an organized care pathway reduces parental stress (29). No such pathway currently exists for LMs.

It would be unrealistic to expect any genetic counseling service to possess detailed information on the increasing number of rare conditions that, like LM, can be diagnosed *in utero*. Written information, whether web-based or in pamphlets, and accompanying photographs cannot replace the in-depth knowledge of specialist multidisciplinary teams such as those which treat vascular anomalies. Close links between such multidisciplinary clinics and obstetric and genetic counseling services are the most effective way to provide parents with the information they need concerning their child's condition and prepare them for postnatal care.

The strength of this study is in the use of individual interviews, which allowed parents to portray their narrative in their own words. Interviewing parents separately has given insights into the experiences of both mothers and fathers, which are not often addressed in the literature. A limitation in this retrospective study is that parents who were not fluent in English were excluded, potentially omitting the perspective of parents who also had to negotiate a language barrier. Recruiting from a single site may also have reduced the scope of the parents' experience. Finally, these results may be similar to those parents who have children with other non-lymphatic malformations that have yet to be studied.

CONCLUSION

The trauma for parents of a prenatal diagnosis of LM is exacerbated by a lack of adequate information and postnatal care plan. The information parents require is largely held by specialist teams located in pediatric hospitals. Closer links between specialized vascular anomalies treatment teams and obstetric and genetic counseling services would facilitate timely parental access to the information and supports parents need.

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