Manuscript title: Being the parent of a child with limb difference who has been provided with an artificial limb: An interpretative phenomenological analysis

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Implications for rehabilitation

To optimise the wellbeing of limb loss peer mentors and maximise the effectiveness of their input:

- It is important to define clearly the role of a peer mentor and the responsibilities this involves.
- Peer mentors should be provided with support and training to increase their confidence and ability to act appropriately when encountering distress
- It is important to provide transparent guidelines and procedures to support peer mentors to minimise concerns over risk and safety
- Feedback regarding how effective the support offered is and how it could be improved should be provided.

Being the parent of a child with limb difference who has been provided with an artificial limb: An interpretative phenomenological analysis

Abstract

Purpose: Rehabilitative care for children with limb difference often includes the provision and use of an artificial (or prosthetic) limb. Of key influence in this process is how parents experience and respond to their child's limb difference and prosthesis use. However, research on this is lacking. Therefore, this study aimed to explore the experiences of parenting a child with limb difference who had been provided with an artificial limb.

Design: Semi-structured interviews took place with seven parents. Interview data was recorded, transcribed and analysed using interpretative phenomenological analysis.

Results: The analysis identified four themes: (1) managing the initial emotional experience through the development of coping resources; (2) opportunities through prosthesis use and its relationship with 'normality'; (3) managing and making sense of social reactions toward their child; (4) the intrinsic role of support: developing a collective connection and enabling shared knowledge.

Conclusions: The study highlighted salient aspects to parents' experiences and sense-making that can inform clinical support. Emotional support, the management of social responses, and the holistic co-ordination of healthcare support with peer support networks are discussed. Healthcare professionals involved in the prosthetic rehabilitation process should look to explore these meanings to help support the management of the child's prosthesis use.

Key Words: Artificial Limb, Child, Limb Difference, Parenting, Prosthesis

Being the parent of a child with limb difference who has been provided with an artificial limb: An interpretative phenomenological analysis

The term limb difference refers to an individual who has been born with a congenital limb deficiency or has acquired limb loss during their life [1]. Within the medical literature, limb differences are sometimes termed limb deficiencies and discussed in the context of a trauma, disease or a congenital condition [2]. Limb difference in children is usually congenital in nature and occurs when part of, or the entire, limb does not form as expected during pregnancy [3]. Complete epidemiological descriptions of limb difference in children are difficult to source and estimates can vary from country to country. Prevalence rates for children born with a limb difference range between 3.5 to 7.1 in every 10,000 births [4]. Children who have experienced a lower limb difference are almost always fitted with a prosthesis (artificial limb) to enhance their functional ability. Children with an upper limb difference will not necessarily always choose to wear a prosthesis as this does not always result in functional gain [5].

Psychosocial Impact on Children

Research exploring the psychosocial impact of limb difference on children and adolescents presents varying outcomes. For instance, an increased prevalence of emotional and behavioural issues and lower social competence have been reported in children with acquired or congenital limb difference, compared to a normative community sample [6]. In contrast, children with upper limb difference have been found to have similar levels of social competence and emotional and behavioural difficulties to a normative reference group [7]. However, greater levels of withdrawn behaviour were found in children with limb difference [7].

A review of the literature concluded the risk of psychosocial difficulties in children with limb difference to be comparable to children without a physical condition [8]. However, it has been suggested that the research literature exploring the impact of living with a congenital condition provides an inconsistent account and that adjustment is likely to be a multi-faceted process involving individual, situational and societal factors, thus making generalisations difficult to capture [9].

Psychosocial Impact on Parents

There is a limited amount of research exploring the experiences of parents of children with limb difference. One qualitative study looked at the response of parents following the birth of their child [10] and reported parental feelings of shock, numbness and disbelief. A subsequent study found that many parents felt healthcare providers did not offer the necessary level of informational or emotional support [11]. Parents also experienced feelings of isolation, worries related to social reactions, and concerns about the future [11]. Building on this research, Andrews, Williams, VandeCreek and Allen [4] found parents of children with congenital limb difference consistently discussed their experiences of healthcare support during their child's first year of life in relation to three themes; attitudes, information and emotional support. This related to the attitudes healthcare providers possessed in relation to disability; the information and knowledge they have and share; and finally, the positive value they placed on the emotional support and compassion healthcare professionals provided. The authors suggest future research needs to continue to explore the impact of disability on parents and the potential mediating role of healthcare professionals.

The Role of Parental Adjustment

Research focusing on the role of parents and family functioning on a child's adjustment to a physical health condition is more substantial. Findings identify a reciprocal role between child adjustment and family functioning [12], with chronic health conditions influencing, and being influenced by, the functioning of families [13-14]. Research has found parental adjustment and family support to be significant factors related to positive psychosocial adjustment in children with a chronic health or disfiguring condition [15-17].

There have been several hypotheses generated in relation to the role of family functioning on child adjustment. For instance, parenting style has been shown to have a direct impact on child outcomes, with Morawska, Calam, and Fraser [18] suggesting parents need to successfully integrate general parenting behaviour and specific health condition management. This can be difficult, particularly when a parent is unsure whether to make allowances for their child or to enforce boundaries. Authoritative parenting practices, that is parenting with high levels of control and warmth, have been found to be associated with positive health related behaviours in children [19]. Parents' own stress levels have also been hypothesised to influence their child's regulation of emotions [20]. This is important to consider as parenting a child with a disability has been found to result in increased parental stress [21-22]. Hall et al. [23] suggest stress may occur through changes to the family system, with the effects potentially seen between parental relationships, the parent-child bond and relationships between siblings.

Prosthesis Use

The utilisation of a prosthesis by children has been researched in the context of functional outcomes, with some interesting differences between upper and lower limb prosthesis use. Ulger and Sener [24] explored the use of a prosthesis amongst children with lower limb difference, both congenital and acquired. They found that after six months of prosthetic rehabilitation, the active use of a prosthesis could support functional gain. Amongst children with upper limb difference, the use of a prosthesis is often rejected by children due to lack of functional outcome [25]. Parental disappointment in function, lack of involvement in treatment, and dissatisfaction regarding perceived support is associated with increased rejection rates [25].

Vasluian and colleagues [26] used a qualitative framework approach to explore reasons for wearing or rejecting a prosthesis in young people with upper limb difference. Focus groups revealed that cosmesis was the prime factor in choosing to wear a prosthesis, with users feeling this enabled participation in social activities and led to less stares from others. Reasons for rejecting a prosthesis centred around weight and limited functionality.

The Current Study

In summary, parents experience challenging psychological responses following the birth of their child with limb difference. Research has also detailed dissatisfaction related to aspects of healthcare support, and worries related to perceived social reactions. The literature suggests parenting a child with a disability is a challenging role and can exacerbate parental stress.

Although the rehabilitation team promote the active involvement of parents in the management of their children’s prosthesis use [27], there is a lack of research exploring parenting a child who has a prosthetic limb. Such research could provide valuable information and guidance to rehabilitation teams in regards to how to support parents and thereby optimise care and outcomes for children with limb difference. Thus, the current study looks to address this gap in the literature using a phenomenological, qualitative approach which prioritises parents’ lived experiences. The study explores pertinent issues for parents, and in so doing make recommendations for effective support. The primary research question was ‘What are the experiences of parents of a child with limb difference who have been provided with an artificial limb, and how do they make sense of these experiences?’

Method

Design

The study was concerned with prioritising parents' lived experiences and therefore a qualitative research methodology was appropriate. A semi-structured interview (appendix A) was designed and utilised to elicit pertinent participant experiences, with the data analysed using interpretative phenomenological analysis (IPA). IPA is committed to exploring meaning and sense-making of a phenomenon amongst a well-defined sample [28]. It has its theoretical origins in phenomenology, idiograpthy and hermeneutics: a focus on experience, the particular and interpretation [29]. In practice, the approach looks to explore how participants experience their world through the analysis of data from small, homogenous samples, acknowledging the active role of the researcher in the interpretation of these experiences. As Smith and Osborn [28] report "the researcher is trying to make sense of the participants trying to make sense of their world" (p.53). The study received institutional ethics committee approval.

Sampling and Participants

Consideration of the sample is an integral aspect to IPA studies. IPA takes an idiographic approach and so involves a detailed analysis moving from individual cases, to iteratively exploring convergences and divergences across participant accounts. Consequently, studies using IPA typically involve small participant samples that share a particular experience.

The criteria for inclusion in the study were being parents of a child with a limb difference who had available to use a prosthesis for a minimum of six months before study participation. The child's age range for inclusion was between 5-16 years old. The rationale for this age range was to seek and capture parents' experiences relating to key cognitive, social and emotional developments for their child, with the child’s language development also a consideration. No restrictions were placed on the nature of the child’s limb difference. Due to funding restrictions relating to the use of a translator, parents were required to converse in English. Parents of a child with a co-morbid health condition which may have limited or precluded prosthesis use were excluded, as were children with a co-morbid physical and/or intellectual disability. The rationale for both inclusion and exclusion criteria related to the preservation of homogeneity which is a fundamental aspect with IPA [29].

Participants were recruited through the social media accounts of online charities supporting both children and adults with limb difference. Recruitment took place over a period of five months. Seven parents took part in the study, five parents resided in the United Kingdom, and two in the USA. Six parents chose to have their interview over the telephone, with one parent choosing face-to-face. Table 1 illustrates the key demographics of the included participants.

[INSERT TABLE 1]

Data Collection

A semi-structured interview schedule (see appendix A) was developed by the research team (who together had expertise in amputation and prosthesis use, paediatric clinical psychology and qualitative research) in liaison with a local limb difference charity. Questions sought to explore salient aspects of parents’ experiences, including their perceived challenges related to the role and the experience of the prosthetic rehabilitation process. The aim was to produce a schedule that would suitably explore the research question, but be flexible enough to enable participants to direct and disclose aspects of their experience relevant to the aims of the research. Interview length ranged from 47 minutes to 66 minutes, with an average length of 57 minutes. All interviews were then transcribed verbatim by the first author, with pseudonyms generated to maintain confidentiality.

Data Analysis

Participant transcripts were analysed one at a time to retain IPA's idiographic focus [30]. First, transcripts were read several times, with the audio recording also played to aid familiarisation. The authors adopted a position of reflexivity during data collection and analysis, involving an attempt to identify and suspend their own personal beliefs and assumptions [31-32]. Initial codes were generated for each transcript. These codes captured the experiences and sense making aspects of participants' responses that related to the research question. These codes were then iteratively grouped together into discrete groups that shared aspects of experience. An interpretative narrative summary was then written for each group of codes that captured the salient experiences and meanings of the participant's account. A title was then given that looked to encapsulate the interpretative narrative; thereby naming the idiographic themes for each participant. Once this process was complete for each participant, themes were synthesised across transcripts, noting convergences and divergences, with a synthesised narrative summary produced for each cluster of themes. Throughout this process, the third author audited each step of analysis.

Results

The analysis led to the generation of four main themes: (1) managing the initial emotional experience through the development of coping resources; (2) opportunities through prosthesis use and its relationship with 'normality'; (3) managing and making sense of social reactions toward their child; and (4) the intrinsic role of support: developing a collective connection and enabling shared knowledge.

Theme 1. Managing the Initial Emotional Experience Through the Development of Coping Resources

All parents in the study recalled strong feelings such as shock when they found out about their child's limb difference. There was a sense that this challenged their pre-existing vision of being a parent: ‘When you are pregnant you think about your child and imagine them doing things like going to brownies or riding a bike or going to school and then obviously, you suddenly think, ‘How is she going to do that?’’ (Lisa).

There was a feeling of uncertainty about the challenges that lay ahead, with most parents having little knowledge of limb difference before becoming a parent:

> I suppose it was a challenge to kind of get our heads around his disability when we first found out, and to learn about what it would mean and the impact it would have on his life, and our lives. (Francis)

Parents discussed a perceived need to protect their child and to provide the necessary conditions to ensure the best outcome. For some, this necessitated a desire to put their child’s needs above their own. Patricia explained: ‘I think I have always done mind over matter and tried to get on with it’; here the metaphor was used to illustrate how she puts her own needs to one side to prioritise her child’s.

In response to the initial emotional experience, parents developed coping resources that helped them to both manage and make sense of the initial emotional experience and the perceived challenges that lay ahead. For instance, Elizabeth and her husband decided not to let limb difference limit their child, and discussed coping through the development of a positive attitude and a proactive approach to overcoming barriers: ‘We both, my husband and I, we don’t really let it be an excuse in his life’. For some parents, there was a sense of advocacy in the way they coped, which seemed to be in response to a perceived duty to protect the needs of their child. Jill reflected on her approach to overcoming barriers related to prosthesis provision: ‘so it is really just advocating’. There was a sense of an organic nature to the coping resources developed, with their ways of coping evolving as their child grew older and in response to ongoing challenges: ‘I’ve always tried to be one step ahead’ (Lisa).

Within some parent accounts, there was also a sense of reflection regarding their initial concerns and fears not being realised, and participants recounted positive experiences of parenting a child with limb difference: ‘It is nowhere near as bad as you paint it to be in your nightmares. And it could actually turn out to be in some weird way to be a blessing or positive experience for all of you’ (Clare).

In summary, the initial emotional experience for parents was difficult for them but was followed by a period during which they tried to adapt to the perceived challenges ahead. In response to these initial feelings, parents developed coping resources to ensure they could fulfil their perceived parental responsibilities, with these coping resources evolving to meet ongoing demands.

Theme 2. Opportunities Through Prosthesis Use and its Relationship with ‘Normality’

Their child’s use of a prosthesis was a central part of parents’ experiences. For most, it afforded opportunities for their child that they did not envisage when they discovered their child’s limb difference: ‘So if he didn’t have the leg he has, he wouldn’t be able to ride a bike, he plays football, he does skiing, any of that, he wouldn’t be able to do’ (Patricia). Jill, whose child plays competitive sport, reflected how the use of a prosthesis vindicated the decision to amputate: ‘I knew that amputation was the best for her because of prosthetics. She would never have done what she has done if we did not choose to amputate, she would be disabled’.

Parents’ described prosthesis use as instilling normality, where their child could engage in activities like their peers and be treated like their peers. Clare discussed how her child’s prosthesis use has enabled a “normal” family life:

> It’s been a normal life, like I worry so much more about like him getting in trouble at school, you know underachieving, him cracking his head open, him falling out of a tree, not being kind to his sister. All these things are much more and part of my mind

> on a daily basis than the fact he has a prosthetic leg, it doesn't even cross my mind, because it has zero impact on the quality of his life.

Patricia discussed a sense of pride in how her child had adapted to his prosthesis and acknowledged this had made things easier for her: 'So the fact that he has just got on with it and doesn't see himself as any different from anyone else, makes it easier for me'.

Conversely, Lisa and Francis, whose children have upper limb difference, were more ambivalent about prosthesis use. Francis critically considered the function of a prosthesis. She felt its use was mainly for cosmetic reasons and made her child feel more different to their peers because of its limited functionality:

> It became very apparent that it was completely unnecessary, [child] didn't particularly take to it, he didn't like it, he just used to pull it off. We were not that enthusiastic either because it just seemed so rudimentary and not really that helpful. (Francis)

In summary, parents of children with lower-limb differences conveyed how the utilisation of a prosthesis enabled opportunities for their children and participation in activities alongside their peers. For these parents, there was a sense that using a prosthesis allowed their child to be treated the same as their peers and enabled a sense of normality. However, this was not the case for parents of children with upper limb loss, where there was less satisfaction with the functionality of a prosthesis.

Theme 3. Managing and Making Sense of Social Reactions Toward Their Child

All parents discussed the challenge of social reactions toward their child and how they managed and made sense of them. For some, this challenge provided a direct conflict and tension to a parental instinct to protect their child. Francis recalled an incident at her child's school where they were not included because of their limb difference: 'It is only isolated incidents but that upsets him and you obviously have then got to be strong and supportive to him but obviously, your heart is breaking inside as well'.

There was a sense of disenchantment regarding members of the public staring: 'I think it can be disappointing. I think you are just disappointed in humanity sometimes, it's frustrating' (Clare). The impact of social reactions seemed to agitate parents' own beliefs that their child should not be treated differently from others: 'Don't stare at them or make them feel under pressure, or make them feel as if everybody is looking at them thinking that they are different' (Patricia).

Parents discussed managing the impact of social stares by attributing them to a natural curiosity to difference, Ruth explained: 'You get a lot of kids staring and looking just out of curiosity, I think mostly that is what it is, it is not nastiness, its human nature to look at something that is a bit different'. Similarly, Clare commented: "Often people aren't staring in a negative way; they are staring in kind of admiration, so we just try to talk to him a lot about it". Jill discussed modelling to her child that others will stare and want to ask questions about their leg. She felt it was important for her child 'not to get frustrated and not to think they [others] are mean'. She felt parents' responses to social reactions were important to consider and would 'dictate how your child feels later in life'.

The experience of social responses left some parents to reflect on societal attitudes toward disability. Some parents took comfort in a greater media profile of disability, with the Paralympics cited as a source of positive visibility. For some, this visibility translated into more inclusive societal attitudes: 'I think there has been a huge rise in the acceptance and the awareness of disabilities' (Ruth). Francis added: 'Just having more people visible in the media and on the television and stuff is really a source of support for the parents and for our children'. Additionally, Francis also felt her child's classmates would develop a greater appreciation of issues related to difference: ‘I think it is positive to other children as well because it sends a message to them that people are different’.

In summary, social responses created a considerable challenge. The experience of negative social responses was difficult for parents and seemed to relate to a desire to protect their child and a belief that they should not be treated differently. There was an aspect of experiencing social reactions that seemed to lead to wider reflections around societal attitudes toward difference, with some parents taking solace from increased media visibility.

Theme 4. The Intrinsic Role of Support: Developing a Collective Connection and Enabling Shared Knowledge

The importance of feeling supported was emphasised in all parent accounts. The support provided parents with a shared connection and a shared understanding of their parenting role. Ruth related the value of parent-to-parent support, which related to a sense of emotional containment and validation:

> I think it is just a comfort blanket, knowing that if you ever have a real fear or a real feeling of anxiety or whatever it happens to be, there is somebody that you can [talk to], you don’t have to keep it in anymore you can let it out. (Ruth)

One perceived benefit of developing a support network related to staying connected and knowledgeable in relation to prosthesis provision. This reflected parents’ initial feelings of uncertainly and the unknowing aspect to becoming a parent of a child with limb difference. Jill referred to her ‘huge support network’ and felt an important aspect of being a parent of a child with limb difference was to stay connected. Lisa discussed how a charity social media account helped her to become aware of what was available through the healthcare service in terms of prosthesis provision: ‘When she started going down the myo-electric journey, the initial ones she had were not brilliant and through a lad I know through [charity], I knew he got one of the latest model ones from a different limb centre’.

Some parents discussed the benefit of peer support in the form of family events or camps for children with limb difference. These events seemed to offer a sense of normalisation of their experiences and a feeling of acceptance:

> There are just loads of kids like [child] and parents like us, you know, sometimes you don’t even talk about limb differences, you can just sort of sit and know that your child isn’t going to be stared at, they are going to be accepted and that everyone is really positive. (Francis)

The importance of feeling supported extended to healthcare providers. Parents valued the relationship with their prosthetist, which related to a sense of trust, and the prosthetist wanting the best outcome for their child: ‘He was clearly wanting the best for [child]. It isn’t just a job to him’ (Clare). However, healthcare support was not always appraised as positive. Parents could experience a lack of emotional support in the immediate aftermath of finding out about their child’s limb difference. This was experienced as a disappointing aspect of care given the important healthcare decisions parents often had to make around this time. Ruth discussed her experience of support when deciding whether to have her child’s leg amputated: ‘I think there should have been something, especially when you are getting told the darkest news that her leg is not going to grow and there is basically nothing we can do about it’.

In summary, developing support networks was highly valued and offered both emotional and practical support. The support offered by healthcare services and professionals was also a prominent narrative in parent accounts. Parents offered a collective regard to the development of a trusting relationship with their prosthetist. Parents discussed a lack of emotional support around the time of their child’s diagnosis, with a sense this was a disappointing aspect of care received given the emotional challenges they faced during this period.

Discussion

The aim of this study was to explore and make sense of the experiences of parenting a child with limb difference who has been provided with an artificial limb. The results suggest that upon finding out about their child's limb difference, whether during pregnancy or birth, parents experience a range of powerful emotions, supporting previous research [10]. Within parent accounts there was a sense of uncertainty about the challenges that lay ahead and a move away from their pre-existing ideas of being a parent. In response to their initial emotional experience, parents developed a variety of coping resources to help them make sense of and manage the perceived challenges ahead. This is in keeping with the resiliency model of family stress, adjustment and adaptation [33], which conceptualises the process of adaptation and resiliency in families as an ongoing, evolving process.

The role of social support, particularly parent-to-parent support was valued by parents in the present study. The positive influence of social support is a consistent presence within paediatric models of adjustment [33-34]. Interestingly, the results of the present study extended parents' perceived value of support to include a more pragmatic aspect of information sharing. Support networks enabled parents to educate themselves around important issues related to their child's limb difference such as prosthesis provision.

The results also highlighted the experience of social reactions for parents. For some, there was a sense of disillusionment regarding members of the public staring at their child, with others choosing to take meaning from this experience in relation to a normal human propensity to look at something that is different. Parents worried about the impact of social stares on their child's self-esteem and confidence: research suggests this is a valid concern [35]. The experience of social responses seemed to lead some parents to reflect more generally about societal attitudes toward disability, with many feeling society is becoming more tolerant and mindful of issues related to inclusivity. Increased media coverage of disability was a source of support for parents, with some citing the Paralympic Games as a positive example. This seemed to give individuals with a disability a platform to showcase their abilities and normalise the use of a prosthesis. This finding supports Gunter’s [36] assertion regarding the educative power of the media, and the widely held belief it can help promote diversity and challenge appearance stereotypes.

A central feature of the experience of parents concerned the meanings attached to prosthesis use for their child; with this aspect of experience novel to the research literature. The results suggested that for most parents, their child’s use of a prosthesis enabled opportunities, social integration and for them to be treated the same as their peers. This finding echoes the work of Murray [37] who focussed on adult users of a prosthesis and the personal and social meanings attached to its use. Murray suggested the personal meaning can go beyond the functional capabilities of the device, and be entangled with more significant meanings, such as the prosthesis enabling the user to feel like they are living a ‘normal’ life, being treated the same as non-users, and enabling independence and social participation.

In the current study, an interesting divergence was found between parents regarding upper limb prosthesis use and lower limb prosthesis use, with the former appearing to take a more overt critical stance regarding its functionality. The issue of functionality has received attention before, with Postema et al. [25] suggesting lack of function is often a pivotal reason for the rejection of upper limb prosthetics by both children and their parents. Lower limb prosthesis use seemed to enable function comparable to same aged peers, and for parents this allowed their child to be treated the same. This was less apparent amongst parent accounts of their child’s upper limb prosthesis use, who were ambivalent regarding its function and use more generally.

Clinical Implications

The results have a number of clinical implications that can help inform effective care for both children and parents of children with limb difference. Firstly, there is a need for service provision to show a greater consideration of parental emotional support. In the UK, for example, hospital services adopt a child-centred approach to care that should consider the support needs of parents to help them understand and cope with their child's health condition [38]. However, the results of the present study suggest a greater focus on the emotional needs of parents should be emphasised.

Consideration and support of parents' own emotional health seems to make intuitive sense with research consistently illustrating a reciprocal role between child and parent adjustment in children with health conditions [34]. Mercer and colleagues [39] recently discussed the delivery of psychological support for children and their families within paediatric settings. They advocate for the need to identify and support parents who may be finding it difficult to cope, as this will ultimately impact their own child's ability to cope. Furthermore, they suggest a role for clinical psychologists to be embedded within multi-disciplinary teams (MDT) and use their skills in consultation, joint-working, training and supervision. This can help to promote issues related to psychological well-being as being everyone's responsibility within an MDT.

Supporting parents to consider their feelings and personal meanings attached to prosthesis use for their child, including issues related to cosmesis and functionality, may help parents to feel more confident in managing their child's use of a prosthesis. Moreover, parents may benefit from exploring their own opinions and views around issues related to visible difference, with some parents reflecting on a change in their own attitudes toward difference and disability. Research suggests a parent's feelings about their child's appearance can be assimilated and internalised by the child, which in turn can influence their own conceptions of body image and feelings of self-worth [40]. Therefore, exploring this with parents in a non-judgemental and non-stigmatizing way could be of value. Given the central role parents play in the decisions and management of their child's prosthesis use, the results advocate for parents' feelings and personal meanings attached to prosthesis use to be explored when engaging within the prosthetic rehabilitation process.

A key clinical implication concerns the co-ordination of healthcare services with relevant third sector voluntary agencies to ensure parent-to-parent support networks can be developed. In addition to the emotional support parents gained from a network of peer support, there was also a practical or pragmatic aspect that related to information sharing and prosthesis provision. Parents perceived lack of information fits with prior research findings [11], and suggests further work need to be done regarding information sharing by healthcare professionals around the time of diagnosis and the birth of their child.

Limitations

It is important to note that as participants were recruited through the social media accounts of online charities, parents that chose not to take part, or parents not involved with such charities, may have different experiences and opinions than those expressed in the current study. In addition, most of the parents' children had congenital limb differences rather than acquired limb loss and used their prosthesis for a long time and from an early age. Although one participant in the present study was the parent of a child with an amputation, caution is required in extrapolating the study findings to study populations with different characteristics.

The retrospective nature of data collection, with parents' recounting their emotional reactions and experiences to their children's limb difference over a long period, presents issues regarding full and accurate recall of information. Further work that examined parents' experiences longitudinally, gathering data contemporaneously, would be valuable in addressing this.

In consideration of the sample, the absence of any fathers in the present research is a limitation. It is conceivable that the results do not portray salient aspects of experience that are relevant to the experiences of fathers. The absence of fathers within parenting research remains an ongoing issue [41].

Of theoretical consideration, the present research was exploratory in nature, using a small but detailed account of parental experiences. It is therefore important to acknowledge that the results are not attempting to generalise to the experiences of all parents of children with limb difference. Smith and colleagues [29] suggest IPA studies can offer theoretical generalisability, which gives the reader the opportunity to assess the results in the context of their professional and experiential knowledge.

Further Research

The present study did not differentiate between acquired and congenital limb difference. While this did not impact the results of the present study, with one parent having a child who acquired their limb difference due to a surgical complication at a young age, future research could explore this further and detail any aspects of experiences that may differ. Once more this could have implications in providing effective support for parents. In addition, the present study identified an interesting divergence in parental accounts regarding the functionality of upper and lower limb prosthesis use. Given the small sample size, it is important not to overstate this finding. However, future research could explore this potential difference further, as well as examining the personal and social meanings attached to prosthesis use by parents and children, in a similar way to the work of Murray [37] with adult prosthesis users.

Conclusion

The findings suggest that parents experience a range of strong emotions as they adjust to their child’s diagnosis of limb difference, with coping resources developed in response to the perceived challenges ahead. For most parents, their child’s use of a prosthesis enabled participation opportunities and facilitated their child being treated like their peers. The ongoing challenge presented by social responses was highlighted, with parents looking to protect their child from any negative impact. Parents drew support from media visibility and a perceived attitudinal shift toward inclusivity. The value of both peer and healthcare support cannot be understated, with the recommendations that services place greater focus on providing emotional support to parents, as well as a more co-ordinated relationship to peer support networks.

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Table 1.

Participant demographics

Participant Pseudonym	Child's Age	Childs Gender	Years/Months prosthesis available	Location of Limb Difference	Nature of Limb Difference	Residing Country	Data Collection Method
Lisa	10	Female	10 years 2 months	Upper Limb	Congenital	UK	Face-to-face
Francis	7	Male	6 years 6 months	Upper Limb	Congenital	UK	Telephone
Jill	14	Female	13 years 3 months	Lower Limb	Congenital	USA	Telephone
Clare	9	Male	8 years	Lower Limb	Congenital	UK	Telephone
Ruth	8	Female	5 years	Lower Limb	Acquired	UK	Telephone
Elizabeth	11	Male	10 years 4 months	Lower Limb	Congenital	USA	Telephone
Patricia	11	Male	8 years 5 months	Lower Limb	Congenital	UK	Telephone

Appendix A: Semi-Structured Interview

Demographic Information

Before commencing the interview could you briefly tell me how old your child is and the nature of their limb difference?

Parenting

What have been the key challenges or adaptations to parenting a child with limb difference?
How have you managed these challenges?
Have there been any benefits?
Has there been any impact to your family system? If so, what are some of the difficulties or positives encountered? Who, if anyone, in the family has been impacted?
How have you managed your own needs when parenting a child with limb difference?

Limb Difference and Prosthesis Use

What was your understanding of limb difference and prosthesis use before you had your child?
What does it mean to you now?
How did you decide for your child to be provided with an artificial limb?
Did you seek support in this decision-making process (family, friends, healthcare professionals)? If so what is your experience of receiving this?
How would you describe your relationship with the healthcare services supporting your child? How have you experienced this support?
Have there been any disagreements with healthcare professionals involved in your child's artificial limb use? If so, how have these been managed? If not, why do you think that is?

Prosthesis Use and Parenting

How has your child adapted to using an artificial limb?
Has this brought any challenges in your role as a parent?
How do you think your child feels about their artificial limb? What experiences have you had that has made you think this?
Have there been any benefits to your child in using an artificial limb?
Do you think your child has been impacted in anyway by having a limb difference? (school, friendships)? Has using an artificial limb changed this in anyway?

Final Thoughts

If you had to give advice for new parents of a child with limb difference what would it be?
If you could give advice or make any changes to the healthcare services involved during your journey of parenting a child with limb difference what would it be?
Specifically, to artificial limb use, what advice would you give to prosthesis services, to consider parents' experiences?

Thank you for taking part, do you have any final thoughts or reflections about your experiences of parenting a child with limb difference?