

## TITLE PAGE

**Title:**

Parental perspective: The role of prostheses and prosthetics services in adjusting to a child's upper limb difference.

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## ABSTRACT

**Background:**

The impact of paediatric upper limb difference may extend beyond the child themselves to their parents and other family members. Previous research has found that feelings of shock,

numbness and loss are common amongst parents and that peer support can be a buffer against stress.

**Objective:**

The current study aimed to explore the experiences of parents of children with limb difference, and the role of services and prosthetic devices in these experiences.

**Methods:**

Nine parents of children with limb difference participated in either a group (n=2) or individual (n=7) interview.

**Results:**

Analysis of the interview transcripts revealed four themes - 'grief and guilt', 'prosthesis as a tool for parental adjustment', 'support' and 'fun and humour'.

**Conclusions:**

Parents may employ coping strategies to help them adjust to their child's limb difference, including use of a prosthesis, accessing support from statutory services and peers, and use of fun and humour within the family.

**Key words:**

upper limb prosthetics; paediatric prosthetics; parental experiences; qualitative research.

## MAIN DOCUMENT

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## **1. Introduction**

Upper limb difference can have both a physical and psychological effect on a child [1]. When seeking support for limb difference at a limb clinic, children may be prescribed a passive prosthesis, a body-powered prosthesis, a myoelectric prosthesis or a task-specific device [2]. Research into the views of children with limb difference has found that they may use prostheses to prevent unwanted attention, assist with self-care activities and for fun [3]. Often, however, children are prescribed with prostheses that attempt to replicate a human hand or 'replace' some function or cosmesis which is perceived to be 'lacking'. This treatment is largely unnecessary and reinforces a medical model view of limb difference, which can be detrimental to a child's development [4].

The experience of disability may be collective rather than limited to and contained within the individual [5]. The lives of family members may therefore be affected and changed profoundly. Therefore, it could be argued that upper limb difference does not only impact on the child or adolescent

themselves but also on their parents and families. The family should, therefore, be at the centre of healthcare services as the constant social environment in the child's life and expert in the child's needs [6] with professionals working collaboratively with children and parents, showing mutual respect for the skills and expertise they bring to the decision-making process [7]. This approach has been found to result in better psychological adjustment of disabled children [8,9] and their parents [10].

Research into the experiences of parents of children with limb difference is limited. Two studies by Kerr and McIntosh examined, from a midwifery perspective, parents' experiences of professionals diagnosing their child's limb difference and of attending support groups [11, 12]. One study revealed that feelings of shock, numbness and loss were common amongst parents when health professionals diagnosed their child's limb difference [11] and the other found that social support from people in a similar situation was an effective buffer against stress [12]. This was due to the positive effects of experiencing belonging to a group of people with a shared experience, feeling understood by others and having the opportunity to provide support to other parents, engendering a feeling of 'closure' [12].

Some more recent qualitative research has explored the experiences of parents of children with limb difference [13, 14]. An action research study identified that attitudes of healthcare providers towards disability, and the information they shared with parents, impacted on the parents' experiences, concluding that further research into parental experiences is needed [13]. Additionally, a phenomenological study identified four themes – coping strategies, prosthesis use, social reactions and support – as central to the way parents of children with limb difference make sense of their experiences [14]. These studies, however, combined the views of parents of children with lower limb difference and upper limb difference and identified that there was a significant divergence in the responses of parents to a prosthesis depending on whether it was for upper or lower limb difference [14]. Parents of children with upper limb difference were found to have a more ambivalent, or even negative relationship with the prosthesis, suggesting that experiences of parents of children with upper limb difference warrants further exploration.

The current study aims, therefore, to build on, and update, the limited research in this area by gathering an in-depth understanding of the experiences of parents of children with upper limb difference.

## **2. Method**

The study used qualitative methodology to develop an understanding of the experiences of parents of children with limb difference, in relation to healthcare services and prostheses. The study was completed as part of a larger research project into the participatory design of paediatric upper limb prostheses [4], conducted within the framework of the BRIDGE method of participatory design [15] and influenced by the transformative research paradigm [16]. Ethical approval for this study was granted by the University of Southampton's Faculty of Health Sciences Ethics Committee (FoHS-ETHICS-2011-075).

### ***2.1 Participants***

Nine parents of children with limb difference participated in the study. This constitutes a subsample of the 34 participants (eight children, nine parents, eight prosthetists and nine occupational therapists) from the larger programme of research, who contributed to the development of new prosthetic devices [4].

Participants were recruited through a national charitable organisation (Reach Charity Ltd: <http://reach.org.uk/>). The charity sent participant information packs to their members and three months later followed up with an email reminder about the study. The packs contained: an introductory letter,

participant information sheet and a reply slip with a return envelope. Nine people returned the reply slip and, after being fully informed of the study procedure, gave written informed consent to participate. Seven of the participants were mothers and two were fathers. None of the participants were related to each other.

## ***2.2 Design***

Each participant took part in either a group interview (n=2) or an individual interview (n=7), depending on participant preference. Both the group interview and the individual interviews lasted for approximately one hour. The group interview was conducted at a central London venue and the individual interviews were conducted in participants' homes. The interviews were transcribed verbatim and analysed using Braun and Clarke's [17] framework for thematic analysis. This involved following the stages of: transcription and immersion; generating initial codes; searching for themes; reviewing themes; and defining and naming themes.

The research was conducted by a paediatric occupational therapist, which could have resulted in a tendency to focus on elements of the discussion that related to participation in daily activities and the disabling impact of unsuitable environments, for example. The research was, however, conducted within a



multi-professional research team to ensure a balanced interpretation of the findings. Meetings with an advisory group were also used as a way to broaden influences on the study and minimise the possibility of the bias of one voice. Additionally, the researcher's personal reflections and ideas were kept in a research journal in order to become aware of biases and preconceived assumptions.

### **3. Findings**

Four overarching themes: 'anxiety and guilt'; 'prosthesis as a tool for parental adjustment'; 'support'; and 'fun and humour' were identified. See table 1 for information about participants and table 2 for verbatim quotes (using pseudonyms to protect anonymity).

*[Insert table 1 here]*

#### ***3.1 Theme one: Anxiety and guilt***

Perhaps due to the often unknown aetiology of congenital limb difference in children, parents described feelings of guilt and loss, questioning if their actions could have resulted in their child's limb difference. These feelings caused huge anxiety amongst new parents, leading them to conduct independent research into the causes of limb difference. This resulted in them becoming very anxious about their child's diagnosis. This

increased anxiety for the parents often led to them wanting to conceal their child's limb difference. Parents also experienced anxieties about their child's future abilities, worrying about developmental milestones. Parents described the process of acceptance and coping with anxiety and guilt as being closely related to a realisation that children with limb difference are capable of reaching the same developmental milestones as their peers and seeing their children achieve these things over time being "*a healer*" (Carl). This developing realisation of their children's capabilities did not however negate their perceived need for their child to have a prosthesis at an early age.

### ***3.2 Theme two: Prosthesis as a tool for parental adjustment***

There was a resounding feeling from the participants that the first prosthesis their child had received, when only a few weeks or months old, was for the benefit of the parents rather than their child. Some parents felt that it was one of the most important prostheses their child had been prescribed because it allowed the parents to do the things they considered to be 'normal' for a parent of a small child: to be able to dress their child in the same clothes and take them to the same places as other children and parents and not to be treated any differently. Some parents reflected on how this seemed trivial to them now and perhaps even felt some guilt about feeling the need to disguise their child's limb difference. Some parents identified

that this need to have a prosthesis to feel ‘normal’ and disguise their child’s limb difference was directly related to a lack of emotional, practical and psychological support regarding their child’s limb difference.

### ***3.3 Theme three: Support***

When discussing the importance of support, participants explored the value of both professional and peer support.

#### *3.3.1 Professional*

Parents talked about a lack of support both prior to and directly after birth or diagnosis having a direct impact on difficulties adjusting to their child’s limb difference and a desire to conceal it. Parents described scenarios in which their situation was treated with insignificance and even flippancy by professionals. There was a feeling that this may have resulted from a lack of knowledge or experience from the professionals making it challenging for them to advise and empathise. Several parents reflected on having experiences with professionals who had no knowledge about working with children with congenital limb difference which may have impacted on the quality of support parents were provided with. Parents talked about being given different and conflicting information from professionals. They reported feeling that they had to be proactive in asking for the help or assessments they felt they needed and in exploring their

child's likely needs or possible diagnoses. This, however, was reported to be extremely difficult for parents, even for those with professional experience themselves, such as Amy, who is a nurse. She described the high emotional intensity of the situation as making her feel as though she was in "*la-la land*" and unable to consider things rationally. Participants used highly charged and emotive language when recalling their child's birth, such as "*frustration*", "*overwhelming*" and "*battle*" and explained how a time which should be full of happy memories is bereft of them as a result of a lack of support.

Participants' reflections on the support they had received from the limb centre included both positive and negative experiences. A prevalent word used to describe the limb service was "*trying*" (Emma, Fiona, Grace, Hannah): families identified that it was very important to them that they felt the staff at the limb centre were willing to try different things and explore options. There was a feeling that trying is important regardless of whether it is successful as it is reassuring for a parent to know that they have done all they can for their child and have been supported in this. Other positive supportive factors exhibited by limb centres were flexibility with appointment times, support in preparing for the next developmental stage and building relationships. Families felt

that limb centres being flexible with appointment times had supported them in maintaining employment and ensuring their child has good school attendance. This level of flexibility is, however, something that appears to differ between services with some families reflecting that because of inconvenient appointment times they were only able to visit the limb clinic in the school holidays and this impacted on frequency of visits. Participants praised staff at the limb centre for helping them to prepare for the next developmental stage and recognised the supportive value of this. They also referred to the staff reassuring their children about future challenges and solutions. This was concerned with staff building good relationships with parents and children, enabling them to feel confident to ask questions or tell staff when they faced difficulties.

Lastly, some families reflected on how well-funded the services they had attended were, which opened up opportunities for families regarding equipment and therapy available to them. Having a full staff team who work closely together was reported to be a positive experience by participants although not something that is assumed to exist in all services.

Not all reflections on the support of services were positive. Several participants identified that they had not received any psychological support or counselling and identified this as

having been detrimental to their coping and acceptance in the early months and years of their child's life.

One participant identified that the child's first prosthesis was an inferior substitute for counselling as it allowed the parent to hide their child's limb difference rather than work through their emotional difficulties and accept it. There was a strong feeling that having counselling services available if needed was very important during the process of acceptance and adjustment to limb difference. Other negative experiences at the limb clinic included parents feeling that they were not listened to by professionals. There was an intrinsic message throughout the interviews that treatment choices should be made by the children themselves and they should be recognised as the experts. The reality expressed by some, however, was that professionals regarded themselves as the experts and attempted to fit the child to the technology available rather than listening to the child and attempting to address their needs and wants.

Finally, in contrast to the well-funded services described by some, other participants identified difficulty with getting what they believed their child needed as a result of funding restrictions and bureaucratic processes that appeared to be service-driven and not client-centred. Participants described being made to "*jump through hoops*" (Grace) to receive a

prosthetic device for their child and described experiences with staff shortages in the services they attended.

### *3.3.2 Peer*

As well as support from statutory services, many participants described the importance of peer support, both in terms of providing emotional support and in sharing practical information. As all of the participants were recruited via Reach Charity Ltd it is perhaps unsurprising that they all expressed how helpful this has been to them in terms of remaining positive and accepting their child's limb difference. Participants talked about seeing children with the same limb difference as their child and feeling reassured by this. Furthermore, participants also talked about seeing older children achieve success being a huge positive influence on both them and their children.

Some participants did however feel that accessing peer support was not always a positive experience as they felt it required them to be "*relentlessly positive*" (Barbara) preventing them from sharing their true feelings.

### ***3.4 Theme four: fun and humour***

Finally, participants reflected on their own familial relationships and the use of humour within these as a way to

help them cope with and accept their child's limb difference.

This was often at the expense of other people who asked unwanted questions and received a humorous response from parent or child as a way to deflect attention and lighten the situation.

Humour also took the form of practical jokes using the prosthesis. Having fun with, and making jokes about, the prosthesis was viewed as a positive experience by participants. It was felt that play, fun and humour are natural responses of children and that using the prosthesis in this way allows the child's difference to be turned into something positive and 'special' about them. In addition, it was felt that fun and play are ways to motivate children to use their prostheses.

*[Insert table 2 here]*

The themes presented provide an insight into the impact of having a child with limb difference and factors promoting or inhibiting emotional adjustment for parents.

#### **4. Discussion**

This study has examined the experiences of parents of children with upper limb difference and the role of the prosthesis within that.



The participants identified that the child's first prosthesis is necessary for parents, to help with their adjustment to the limb difference, as opposed to being needed by the child.

Participants reflected that this need may not have been apparent had they been offered counselling to help them deal with the emotions of grief and guilt that they were experiencing. Kerr and McIntosh's [11] study of parental experiences of the disclosure by health professionals of a child's limb difference revealed similar reactions. There is a substantial body of literature describing the emotional and psychological stresses parents of a disabled child may experience including feelings of grief, loss and guilt [18, 19]. Parents of disabled children are particularly vulnerable to stress [20, 21] and parental distress and family functioning affects a child's cognitive, behavioural and social development [22]. Therefore, a lack of psychosocial support for parents may result in high levels of parental distress, which may also impact on the child's well-being [23]. As a temporary coping strategy, denial can be useful in giving parents time to adjust to the situation [24].

Participants appeared to be describing using denial as a coping strategy when using a prosthesis as a tool to disguise their child's limb difference. If the parents who participated in this study had been given the opportunity to discuss difficult

emotions this may not have been necessary. The evident lack of availability of counselling for the participants in this study may represent a medical model approach to childhood limb difference. Practicing within the medical model would involve focusing on the child's impairment and the prevention of disability resulting from this impairment, rather than considering the broader needs of the child and family. In a medical model approach, family/parental stress is viewed as directly occurring as a result of the impairment: treating the impairment is, therefore, viewed as treating the stress [21].

The service specifications for Prosthetic Specialised Services for People of all ages with Limb Loss [25] state that a “counselling service must be provided by clinical counsellors who have experience of working in a rehabilitation setting”, available not only to the person with limb difference but their relatives and carers as well. This may reflect a move in services towards a more social model perspective with a broader focus that takes account of social and environmental factors.

Participants in the current study expressed that being offered counselling at the time of diagnosis, whether this was *in utero* or following birth, would have been a positive experience for them. Setoguchi [26] recognised the significance of early support for parents, advocating that parents need to have their

questions answered as soon as possible and to be given the opportunity to express their feelings.

Many of the participants discussed the value of peer support received through Reach Charity Ltd. This is in line with Kerr and McIntosh's [12] findings from their qualitative study into the impact of parent-to-parent support on coping with having a child with limb difference. Participants also talked about Reach Charity Ltd being an excellent source of information (which was sometimes felt to be lacking in statutory services). Parents described peer support as being most important early on in their journey but as they become more experienced as a parent of a child with limb difference they transitioned from *supported* to *supporter*, which was viewed as a positive experience. This was also expressed by the participants of the Kerr and McIntosh study who found that providing support to other parents engendered a feeling of 'closure' [12]. Some participants in the current study did however feel that accessing Reach Charity Ltd was not always a positive experience, highlighting the need to consider that peer support is not always helpful and may not be appropriate for everybody.

## **5. Conclusion**

Parents of children with limb difference may experience complex emotions when adjusting to their child's limb

difference. A common coping strategy amongst the participants of the current study was to use a prosthesis to disguise their child's limb difference. However, this may be more representative of denial than acceptance, and may be unnecessary if other coping strategies are available, such as access to appropriate support.

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### **Ethical Considerations**

Ethical approval for this study was granted by the University of Southampton's Faculty of Health Sciences Ethics Committee (FoHS-ETHICS-2011-075). Written informed consent was obtained from all participants.

### **Conflict of Interest**

The authors have no conflicts of interest to report.

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## Tables

| <b>Pseudonym</b> | <b>Participant information</b> |
|------------------|--------------------------------|
| Amy              | Mother of 14 year-old girl     |
| Barbara          | Mother of 14 year-old girl     |
| Carl             | Father of 12 year-old boy      |
| Deborah          | Mother of 15 year-old boy      |
| Emma             | Mother of 9 year-old boy       |
| Fiona            | Mother of 9 year-old girl      |
| Grace            | Mother of 8 year-old girl      |
| Hannah           | Mother of 10 year-old boy      |
| Ian              | Father of 14 year-old girl     |

Table 1: Pseudonyms and participant information

| Theme   | Participant Quotes   |
|---|--|
| <b>Anxiety and guilt</b>                            | <p><i>“All the time you’re searching and trying to work out what’s happened, wondering whether you did anything” (Amy).</i></p> <p><i>“... and then you’re looking into things and finding out about syndromes where there’s brain damage as well. And then, when [my daughter] was about five days old, they sent me all this information with extremely deformed children, hydrocephalus, microcephalus, children with limbs missing, thalidomide children... I can remember looking at this and just feeling totally overwhelmed.” (Amy).</i></p> <p><i>“It was all the thing of me trying to, well in a way hide it. You try to hide things and you can’t, you know. So I’d have her all wrapped up trying not for her arm to come out. Really, you know, sad, but we had no support.” (Barbara).</i></p> <p><i>“How’s he gonna ride a bike? How’s he gonna tie his shoelaces? What’s he gonna do about... doing a tie up? [...] all basic things in life” (Carl).</i></p>   |
| <b>Prosthesis as a tool for parental adjustment</b> | <p><i>“So that one [the first prosthesis] I think was the most important one of them all. Yes that arm was very important because at that stage you just want your child to have two hands and it did help us a lot.” (Deborah).</i></p> <p><i>“[The need for the first prosthesis] sounds so trivial now because I don’t even notice it on him anymore that he’s missing a lower arm.” (Deborah).</i></p> <p><i>“I think if we’d had more support when [my daughter] was born because, we didn’t know obviously then that [my daughter] had the limb deficiency, we had no support at all... it was quite inhumane really. I think that if I’d had the right support then, I don’t think I would have been concerned in baby clinic if people were looking at her.” (Amy).</i></p>  |
| <b>Support</b>                                      | <p><i>“There was only two babies born in the hospital that night and the paediatrician came round in the morning and said ‘Hello, have you got anything that you’re worried about your baby?’ and I said ‘well, he’s only got one hand.’ ‘Oh, yeah I heard there was a baby born like that last night’ she said.” (Deborah)</i></p> <p><i>“We had to push to get tested that there was nothing else wrong because, as young parents, and your child’s born, and you’re thinking ‘ok I can see there that there’s something wrong’ but you’re thinking that ‘there might be a lot more that’s wrong that I can’t see’. We had to really push to get checks done.” (Deborah).</i></p> <p><i>“And I still get really annoyed that that happened to us and we were in that situation because when I look back at [my daughter’s] birth I’ve got no good memories. There’s nothing nice really to remember because of all that, which is wrong really. And that’s what you’re left with.” (Amy).</i></p> <p><i>“... at least we were able to go to the limb centre and have a go and then she could make her own mind up that it wasn’t very successful. So even when things don’t work the fact that we can try is better than just saying ‘no it won’t work’.” (Ian).</i></p> |

|                              |  |
|------------------------------|--|
| <p><b>Fun and Humour</b></p> | <p><i>“I’m working full-time so it’s very difficult for me to get to appointments. They only have morning appointments Monday to Friday so it’s quite restrictive.” (Barbara)</i></p> <p><i>“I do think they do a brilliant job really. And a good job of building relationships because [my daughter] really likes going. She really enjoys going and the guy who does her arm, who measures her and does all her arms has known her since she was a baby so it’s the same person so that is good.” (Grace)</i></p> <p><i>“She’s been lucky because the prosthetic technician and the OT really work closely together so I think she’s been lucky because she’s had really good experiences.” (Emma).</i></p> <p><i>“They did offer counselling but it never materialised which is a shame because I think I would have benefited from that. But, you know, there wasn’t a counsellor, so what could they do?” (Barbara).</i></p> <p><i>“Our prosthetist has always been very keen on [my daughter] having cosmetic limbs... I sometimes felt he was suggesting [my daughter] might want to have a hand for cosmetic reasons. ..On several visits he’s said ‘have you ever considered a cosmetic arm? You really ought to think about it because it would balance you up visually’... he seemed to have his own agenda rather than listening to [my daughter] and noticing that she’s confident and doesn’t have problems at school. He seemed to have his own agenda that he wanted to put forward... He had his own ideas. He’d been there a long time, he’s very senior, really committed and enthusiastic but he had his own ideas that he was quite keen on. But I don’t think he was letting her needs lead him, I think it was the other way round.” (Barbara).</i></p> <p><i>“So we went to our limb centre but they had no occupational therapist at the time because she was on maternity leave and they had no cover.” (Amy).</i></p> <p><i>“They were down a prosthetist or something so we resolved it ourselves again.” (Barbara).</i></p> <p><i>“Reach was very important. It’s a 1 in a 100,000 chance I believe and it’s amazing when you go to Reach and you see, you know the first magazine you pick up and there’s children in there with the same arm as your child. That gives you so much reassurance that, you know they’re so identical, they’re so identical, and more often than not it’s the left arm. I’m not saying there’s loads out there but to see someone with exactly the same, it’s a huge help as a parent.” (Deborah).</i></p> <p><i>“There’s another young lady who goes there with a similar limb to [my daughter], she’s about 18, and she’s a bronze medallist in the javelin. So I think meeting her has really shown [my daughter] what she can achieve.” (Ian).</i></p> <p><i>“You just get fed up with kids asking questions and I say ‘yeah he got attacked by a crocodile and it bit off his arm’. And you just look at their faces and they’re horrified.” (Carl).</i></p> |
|------------------------------|--|

Table 2: Themes as illustrated by verbatim participant quotes.