

## **Prosthesis use in times of transition for children and adolescents with upper limb difference.**

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### **Abstract**

Children and adolescents with upper limb difference are often prescribed prosthetic treatment. It is widely recognised, however, that, as a child grows and develops, their interests and skill levels change impacting on their desire for a prosthesis. This study aimed, therefore, to examine the views of children and adolescents with limb difference on the use of prostheses during times of transition. Eight children and adolescents with limb difference participated in the study. Each participant took part in a semi-structured individual interview (n=4) or a focus group (n=4). The participants talked about using their prostheses during times of transition or when meeting new people to help them feel more self-confident, prevent unwanted attention and adhere to cultural and social expectations. Use and non-use of prostheses can be a regularly changing pattern throughout a child or adolescent's development. Their decision about whether or not to use a prosthetic device is a legitimate choice guided by their current goals and should not be described as 'rejection'.

## **Introduction**

Children and adolescents with upper limb difference are often prescribed prosthetic treatment: they may be issued with a passive prosthesis, a body-powered prosthesis, a myoelectric prosthesis or a task-specific device (Broomfield 2009).

Upper limb difference refers to the congenital absence or malformation, or absence due to surgical or traumatic amputation, of any part of the arm or hand. A

myoelectric prosthesis uses electromyographic signals from voluntarily contracted muscles within a person's residual limb to control the movements of the prosthesis (Watve et al., 2011). Myoelectric prostheses combine looks and functionality as they can have cosmeses, which have the appearance of a real hand, but are more useful than passive prostheses when it comes to performing activities of daily living (Egermann et al., 2009). It is common practice for children to be prescribed with general purpose body-powered and/or passive prostheses, as opposed to task-specific aids (Shaperman et al 2003). This practice is not, however, supported by research which has concluded that, as opposed to general purpose prostheses, children should be provided with a range of task-specific prosthetic options so that they can select the most appropriate device for the desired use (Crandall & Tomhave 2002; James et al 2006; Buffart et al 2007).

Furthermore, it is widely recognised that, as a child grows and develops, their interests and skill levels change impacting on their desire for a prosthesis for function or aesthetics (Patton 2004). It is suggested that children of primary school age, having previously been accepting of prostheses, may opt not to use them as they may become a hindrance in play and activities at this age (Celikyol, 1984). During adolescence, however, appearance may become a more valued attribute and leisure

or work activities may be more demanding bimanually (Celikyol, 1984). Aesthetics and functionality of prostheses may therefore become more important to young people at this age (Celikyol, 1984).

To further understand the changing prosthetic needs and wants of children and adolescents with limb difference, exploration of patterns of wear are important. This study aimed, therefore, to examine the views of children and adolescents with limb difference on the use of prostheses during times of transition.

## **Method**

This study was conducted as part of a larger body of research into the participatory design of upper limb prostheses with children and adolescents (Sims 2014). The larger study was conducted within the framework of the BRIDGE method of participatory design (Iversen & Brodersen 2007) and influenced by the transformative research paradigm (Mertens 2005). Ethical approval for this sub-study was granted by the University of Southampton's Faculty of Health Sciences Ethics Committee (FoHS-ETHICS-2011-056).

### *Participants*

Eight children and adolescents 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 devices (Sims, 2014). Participants were recruited through a charitable organisation (Reach Charity Ltd: <http://reach.org.uk/>). They provided written informed assent to participate,

supported by written informed consent from a parent or guardian. Participants were aged between eight and fifteen years old with a mean age of eleven. For details relating to gender, aetiology of limb difference, level and side of limb difference and experience of prosthesis use, see table 1.

		<b>Male</b>	<b>Female</b>
	No. of participants	4	4
<b>Aetiology</b>	Congenital	3	4
	Acquired	1	0
<b>Side</b>	Left	2	1
	Right	2	3
<b>Prosthesis Use</b>	Daily	1	1
	Occasionally	2	2
	Previously used	1	1
	Mean age	11	11

Table 1: Characteristics of Participants

### *Design*

Each participant took part in a semi-structured individual interview lasting for approximately 1 hour (n=4) or a focus group lasting for approximately 90 minutes (n=4). Interviews took place in the participants' homes and the focus group was carried out in a central London meeting room. Data was transcribed verbatim and analysed using thematic analysis (Braun & Clarke 2006). The stages of thematic analysis, as outlined by Braun & Clarke (2006) were followed: transcription and immersion; generating initial codes; searching for themes; reviewing themes; and defining and naming themes.

## Findings

The participants talked about using their prostheses during times of transition or when meeting new people to help them feel more self-confident, prevent unwanted attention and adhere to cultural and social expectations. These three themes will be discussed in more detail in the following section. Illustrative quotes will be presented verbatim, using pseudonyms to represent participants (with real ages provided).

### *Theme one: Using the prosthesis to increase self-confidence*

Use of prostheses was described as being more prevalent during times of transition, such as changing schools or classes or going to interviews. Some participants explained that the reason for this was that wearing a prosthesis gave them more self-confidence:

*"It was handy when I started high school because it gave me more confidence."*

*(Laura, aged 14)*

Using the prosthesis in this way enabled participants to develop their confidence so that they no longer felt the need to wear one:

*"There'd be no point in me wearing it now because I'm fine with it [...] so I just stopped wearing it." (Laura, aged 14)*

### *Theme two: Using the prosthesis to prevent unwanted attention from others*

Participants described using their prostheses to deal with unwanted attention, especially when meeting new people. They used their prosthesis in situations where

they would encounter people they didn't know, to prevent them from asking unwanted questions. The below quote from Becky, 8, makes it clear that the assumptions people make about her because of her limb difference can be hurtful:

*"[...] if they can see and they come up to me and say "Hey, you've got one hand" that might make me feel in a way sad. But, then if they didn't like, if they saw and then didn't make an opinion on it I wouldn't mind that." (Becky, aged 8)*

The unwanted attention the participants described included staring, asking questions and teasing, such as:

*"[...] say if I've had a bad day at school I normally wear it the next day. I don't know why. Like, people are teasing me or something." (Becky, aged 8)*

On further discussion with Becky (8) it became apparent that "a bad day at school" referred to receiving too much unwanted attention from others and being teased by her peers and called names because of her limb difference.

The participants described wearing prostheses to prevent unwanted attention and teasing at school as well as in other settings (such as when out in public), particularly in situations where they were likely to encounter people they did not know. Emma (9) talked about wearing her prosthesis at school to prevent getting unwanted attention from the younger children:

*"[...] It sometimes helps when I'm in assembly because all the little kids like stare and I find it quite annoying." (Emma, aged 9)*

*Theme three: Using the prosthesis to adhere to cultural and social expectations*

Inherent in this desire to deflect unwanted attention was a feeling that other people, and the participants themselves at times, viewed them as 'different' as a result of their limb difference. Being 'othered' in this way could cause embarrassment and isolation for the participants. Anna (aged 14) remembered a time when she was younger and was required to wear gloves as part of a costume:

*"[...] We had this dancing thing, where we had to wear, everyone had to wear, two blue gloves, and so I had one, a cosmetic hand, so that I could wear two blue gloves as well. I was embarrassed that everyone else had two and I only had one."*

Additionally Emma (aged 9) explained that she had to have a prosthesis to complete her cycling proficiency test, although she can cycle without one:

*"I have to get [a prosthesis] for my cycling test [...] I think I'm going to have two brakes on the same side but I've got to wear a prosthetic." (Emma, aged 9).*

However, the participants recognised that all people are individuals and, by definition, 'different' but they felt that other people did not always appreciate this:

*"[...] When people say 'Oh look you've got one hand' then I usually just say 'Well, you're different too aren't you' [...] I think that everybody's really the same because*

*they're different because everyone is different which makes everybody the same [...]"*

*(Becky, aged 8)*

Being identified by others as 'different' appeared to lead to a desire by the participants to meet others with limb difference, perhaps owing to a yearning for a sense of belonging and sameness:

*"[...] it would be quite cool if there was someone [at school] with one hand and we could make friends, but then it's not very likely that there is going to be in that particular place." (Becky, aged 8)*

To summarise, children and adolescents may find their prosthesis useful for developing self-confidence and dealing with unwanted attention from others during times of change and transition. Understandably, they look for strategies, such as using prostheses, to prevent or reduce this attention. The participants appear to value 'fitting in' and being like others but they also demonstrate that being an individual is important to them.

## **Discussion**

Many of the children and adolescents who participated in the study used a prosthesis to prevent unwanted attention and questions from others and to "fit in" with externally imposed expectations (such as wearing gloves in a dance show). Being viewed as different as a result of their limb difference could result in feelings of embarrassment and isolation for the participants. This reinforces the notion of disability as a socially constructed phenomenon (Shakespeare and Watson, 2002)



as it is not functional impairment resulting from having limb difference that has resulted in these children and adolescents using prostheses. It is, however, the response of individuals and society to limb difference that has warranted the use of devices for them. Societal norms and regulations were also seen to impact on this. The need to use a prosthesis to conform with what is considered the safe or correct use of an item designed for use by a person without limb difference (such as a car or a bicycle) also reflects the disabling of a person by their environment (physical, social and institutional).

Changes in frequency of use of prostheses as related to age and transition were described throughout the data, challenging the use of the term 'rejection' to describe a non-wearer of prostheses, which is prevalent in much literature about children with limb difference. It seems evident that use and non-use can be a regularly changing pattern throughout a child or adolescent's development. Their decision about whether or not to use a prosthetic device is a legitimate choice guided by their current goals (regarding developing confidence, avoiding attention and adhering to social and cultural expectations). Having a prosthesis may become more important to a child or adolescent during times of transition, such as moving to secondary school or university or starting a new job. Use and non-use can, therefore, be a regularly changing pattern throughout a child or adolescent's development, as described by Patton (2004). Children's needs and interests may change rapidly as they are growing and developing: prolonged periods waiting for an appropriate prosthetic device may result in the device, when eventually issued, no longer meeting the child's needs or expectations.

## **Conclusion**

Children's and adolescents' decisions about whether or not to use prosthetic devices may reflect their current goals with regard to developing confidence, avoiding attention and adhering to social and cultural expectations. Therefore the term 'rejection' should be used with great caution when describing non-use of prostheses. It is laden with judgement about the decision not to use a device and implies a permanent stance rather than what is likely to be a more complex, changing and situation-specific pattern. Changing the language used in clinical settings to describe children's choices with regard to using or not using prostheses will help to recognise not using prostheses as a legitimate treatment choice. Occupational therapists need to have the confidence to recognise that prosthetic management is not always the best treatment for children and young people and to explore alternative interventions.

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