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2
3 *Full title:* Children's and adolescents' views on upper limb prostheses in relation to their
4
5 daily occupations.
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10 *Short title:* Children's views on upper limb prostheses
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39

40 *Abstract*
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42 **Introduction**

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44 Prosthetic treatment is widely used for children and adolescents with upper limb (UL)
45 difference, for functional benefit, cosmetic restoration or performance of specific activities.
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47 Children and adolescents feel, however, that prostheses do not help function, are
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49 uncomfortable, are unreliable, are heavy and are not aesthetically acceptable. This research
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51 aims to develop an understanding of children's and adolescents' views on UL prostheses in
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53 relation to their daily occupations.
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58 **Method**

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3 Eight children and adolescents with UL difference participated in a focus group (n=4) or an
4 individual interview (n=4). Data was analysed using thematic analysis.
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7 **Results**

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10 Participants described both positive and negative views of their prostheses. Participants
11 described experiences where their prosthesis was helpful to them for social interactions, when
12 playing and in self-care and productive activities. However, participants also described
13 choosing not to use prostheses due to lack of functional benefit, causing a hindrance in
14 certain activities and restriction of movement.
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21 **Conclusion**

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24 Prostheses can be useful tools for occupational participation for children and adolescents.
25
26 General purpose functional prostheses for children and adolescents can result in the
27 prosthesis not being useful, becoming a hindrance and restricting movement. Task specific
28 devices can overcome these issues to help children and adolescents in social interactions,
29 when playing and in carrying out self-care and productive activities.
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38 *Key Words:* Paediatrics, Upper Limb, Prosthetics, Qualitative Research
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43 **Introduction**

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45 Upper limb difference can have both a physical and psychological effect on a child (Smith,
46 2006). Physical impacts may include asymmetrical development of the spine, postural
47 problems, back pain (Broomfield 2009) and overuse syndrome from increased workload for
48 the remaining arm and compensatory movement strategies (Peterson 2011).
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54 Developmentally, children may struggle with playing with objects in midline, sitting balance,
55 crawling, walking and bimanual skills (Ibbotson 2002). Psychosocial impacts may include
56 lower quality of social activities than peers (Michielsen et al 2011), greater behavioural and
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3 emotional problems, lower social competence and challenges to developing positive body
4 image (Winchell 1996). Occupational therapy aims to limit the negative physical and
5
6 psychological effects of upper limb difference for children and adolescents and promote
7
8 active and independent participation in daily occupations. Occupational therapy can include
9
10 adaptation of activities in the areas of self-care, work and leisure (Dillingham et al 2002),
11
12 such as how to carry out activities using one-hand or with feet (Hanspal 2003), and the
13
14 provision of upper limb prostheses for functional benefit, cosmetic restoration or performance
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16 of specific activities.
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24 Non-use rates of upper limb prostheses amongst children vary widely throughout the
25
26 literature but they have, in some studies globally, been reported to be as high as 50% (Shida-
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28 Tokeshi et al., 2005). Studies relating to children's general satisfaction with prostheses have
29
30 found that prostheses do not help children's function, are uncomfortable, unreliable, too
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32 heavy and not aesthetically acceptable (Biddiss and Chau, 2007; Pylatiuk et al., 2007;
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34 Routhier et al., 2001; Wagner et al., 2007). Exploring and understanding children's and
35
36 adolescents' views about, and use of, prostheses within the context of their daily occupations
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38 is needed to guide occupational therapy practice and ensure that provision of prostheses is an
39
40 effective and positive intervention for children with upper limb difference.
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47 Previous research has used parent proxy reports or quantitative methods to explore the views
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49 of children. A drawback of parent proxy reports is that they rely on adults having the ability
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51 to know what children think and feel, which is an outmoded concept (O'Kane 2008).

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53 Additionally, the reality of how disability and technology affect an individual may be
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55 subjective in nature. Sheffler et al (2009) compared self-report with parent proxy report of
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3 function and quality of life amongst children with limb difference and found that parents
4 underestimated their children's physical and social function and overestimated their comfort.
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10 Qualitative research that directly addresses children's experiences and viewpoints is needed.
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12 Furthermore, from an ethical perspective, Article 12 of the United Nations Convention on the
13 Rights of the Child (1990) states that children have the right to say what they think about
14 anything that affects them and that what they say must be listened to carefully. Using
15 qualitative methods ensures that the factors and areas that are important to the participant are
16 highlighted to the researcher, allowing participants to speak in their own voice, rather than
17 being confined to categories imposed on them by others (Mack et al 2005).
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28 This study aims to explore children's and adolescents' views on UL prostheses to develop an
29 understanding of prostheses in relation to children's daily occupations.
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35 *Literature Review*

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37 Prosthetic treatment is widely used for children with upper limb difference, leading to
38 prescription of prostheses for functional benefit, cosmetic restoration or for performance of
39 particular activities. In current practice, there are three main types of prosthesis that may be
40 prescribed for children - passive prostheses, body-powered prostheses and myoelectric
41 prostheses (Broomfield, 2009).
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51 A passive prosthesis is designed to look as natural and aesthetically pleasing as possible
52 (Broomfield, 2009) and is shaped and coloured to match the unaffected arm (Watve et al.,
53 2011). A passive prosthesis is usually the first prosthesis a child will be prescribed with
54 (Watve et al., 2011). Passive prostheses are lightweight and do not usually contain moving
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3 parts (Broomfield, 2009). Despite the drawback of a lack of movement, a passive prosthesis
4
5 can still be useful. The child can support objects with the prosthetic hand (Broomfield, 2009)
6
7 and it may also perform a passive assistive role to the unaffected arm, such as steadying a
8
9 piece of paper when writing (Watve et al., 2011).
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14 A body-powered prosthesis, such as a voluntary opening/closing split hook or hand, contains
15
16 moving parts and is, therefore, more practical for use in activities of daily living (ADLs) than
17
18 a passive prosthesis (Broomfield, 2009). A body-powered prosthesis is an arm that utilises a
19
20 harness and cabling to control a hand (also known as a terminal device) and an elbow unit
21
22 (Muzumdar, 2004). The harness system is controlled by gross body movements (such as
23
24 scapular abduction) (Muzumdar, 2004). It is simple in design, making it highly durable and
25
26 suitable for use in tasks that involve water, dust, and other conditions that could damage an
27
28 electric prosthesis (Muzumdar, 2004). Some users of body-powered prostheses report that the
29
30 cable tension simulates proprioception, enabling enhanced spatial awareness and allowing the
31
32 wearer improved feedback on the position of the prosthesis (Muzumdar, 2004). Body-
33
34 powered prostheses are heavier than passive prostheses, which may cause physical strain to
35
36 be put on a child's body, resulting in discomfort (Biddiss and Andrysek, 2011).
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44 Myoelectric prostheses offer the advantage of combining looks and functionality as they can
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46 have cosmeses, which have the appearance of a real hand, but are more useful than passive
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48 prostheses when it comes to performing ADLs (Egermann et al., 2009). A myoelectric
49
50 prosthesis uses electromyographic signals from voluntarily contracted muscles within a
51
52 person's residual limb (Watve et al., 2011). These signals are detected by sensors on the
53
54 surface of the skin and control the movements of the prosthesis. Myoelectric prostheses tend
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3 to be heavier than other prosthetic options and are susceptible to damage when exposed to
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5 moisture (Muzumdar, 2004).
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10 In addition to commercially available prostheses for children and adolescents, there may also
11
12 be a need for custom-made task specific devices (Broomfield, 2009). Much research has
13
14 suggested that task specific devices are most useful for children as they can be used for
15
16 specific activities, making them most appropriate for the desired use (Buffart et al., 2007;
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18 Egermann et al., 2009; James et al., 2006). This has been evidenced in the recent provision by
19
20 the UK Department of Health (DoH) (2017) for the funding of sports prostheses for children
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22 in England who have experienced limb loss or who were born with a limb difference, to
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24 enable them to engage in physical activity and sports.
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31 Different types of prostheses offer different levels of functional and cosmetic benefit to their
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33 users. For over 30 years it has been recognised that a child is likely to go through different
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35 stages of prosthesis use, just as they will go through different developmental stages (Biddiss,
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37 2010; Celikyol, 1984; National Academies of Sciences, Engineering, and Medicine 2017;
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39 Patton, 2004; Sims, 2018). It is suggested that children of primary school age, having
40
41 previously been accepting of prostheses, may opt not to use them as they may become a
42
43 hindrance during this very physically active developmental stage (Patton, 2004). During
44
45 adolescence, however, both aesthetics and functionality may become more important to the
46
47 young person as appearance becomes a more valued attribute and leisure or work activities
48
49 become more demanding bimanually, requiring fine prehension (Patton, 2004).
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57 Clinical decisions regarding which type of prosthesis is most suitable for a child are likely to
58
59 be guided by the child's age and proposed use for the device, as well as the cost of the device
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3 and the funds available, leading to variations in treatment (Broomfield, 2009). Furthermore,
4 since Celikyol's (1984) guidance was published, huge technological advances have occurred
5
6 both in prosthesis development and in the environments with which children interact.
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12 Current research to explore children's and adolescents' views about, and use of, upper limb
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14 prostheses in daily occupations is needed to provide additional evidence to guide
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16 occupational therapy practice. This research aims to develop an understanding of children's
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18 and adolescents' views on upper limb prostheses in relation to their daily activities.
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22 23 24 *Method*

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26 Ethical approval for the study was granted by the University of Southampton's Faculty of
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28 Health Sciences' Ethics Committee in June 2011 (FoHS-ETHICS-2011-056).
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32 33 **Methodology**

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35 This study formed part of a larger programme of research which used an emancipatory lens
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37 (Mertens, 2015) to carry out the BRuger Involvering i Design, GEntænkt (BRIDGE)
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39 (English: User Involvement in Design, Revised) (Iversen and Brodersen, 2008) method of
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41 participatory design to develop new upper limb prostheses with children and adolescents,
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43 resulting in the production of several prototypes of cost-effective task-specific prosthetic
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45 devices (Sims et al, 2017).
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50 51 **Participants**

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53 Eight children and adolescents with below elbow upper limb difference participated in the
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55 study. They were recruited through a national charitable organisation (Reach Charity Ltd:
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57 <http://reach.org.uk/>). The charity sent participant information packs to their members and
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3 three months later followed up with an email reminder about the study. The packs contained:
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5 an introductory letter, two participant information sheets (one for parents and older children
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7 and a separate, simpler information sheet for children aged 7-11 years) and a reply slip which
8
9 included some basic screening information about the respondents. The parents of eight
10
11 participants contacted the researcher after receiving the information pack or reminder email
12
13 and their children were recruited to participate in the study.
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17 The eight participants of this study constitutes a subsample of the 34 participants (eight
18
19 children/adolescents, nine parents, eight prosthetists and nine occupational therapists) from
20
21 the larger programme of research, who contributed to the development of new devices (for
22
23 further information, see Sims et al, 2017). Table 1 provides an outline of the demographic
24
25 characteristics of the participants. Written informed consent was given by parents of
26
27 participants, and participants provided written informed assent.
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33 *[Insert table 1 here]*
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38 Pseudonyms are used throughout the results to protect anonymity, but actual ages are
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40 provided.
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44 **Design**

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46 Participants were offered the choice of participating in a focus group or individual interview.
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48 The research combined focus groups and interviews for both pragmatic and confirmatory
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50 reasons. The focus group and interviews used the same questioning guide and included
51
52 questions about what the participants liked or did not like about their prostheses, the activities
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54 they could or could not do with their prostheses and what their ideal prostheses would be like.
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3 Areas for discussion were based on previous work by Donovan-Hall (2010). See appendix for
4
5 interview and focus group guide.
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10 Four participants chose to take part in a focus group, lasting approximately 90 minutes and
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12 four participants chose to participate in an individual interview lasting approximately 60
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14 minutes. The focus group was carried out in a central London location and interviews were
15
16 carried out in participants' homes. No financial incentive was offered for participation, but
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18 participants were reimbursed expenses and provided with a certificate of participation.
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20 Data was transcribed verbatim and analysed using thematic analysis (Braun and Clarke,
21
22 2006). The stages of thematic analysis, as outlined by Braun and Clarke (2006), were
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24 followed: transcription and immersion; generating initial codes; searching for themes;
25
26 reviewing themes; and defining and naming themes. Analysis was conducted on each
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28 transcript individually before combining to develop the themes.
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35 **Trustworthiness and credibility**

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37 Combining two data collection methods (focus groups and interviews) enhances credibility of
38
39 the findings through triangulation of methods (Guba and Lincoln, 1985; Shenton, 2004).
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41 Credibility was further enhanced by conducting a pilot focus group (not included in the study
42
43 findings) in order to improve skills in focus group facilitation, as it is acknowledged that the
44
45 facilitator's role is crucial to the quality of data collected (Kennedy et al., 2001). Further
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47 details on the pilot focus group can be found in Sims (2017).
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54 Throughout the research process, reflections and ideas were kept in a research journal to
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56 consciously acknowledge any biases. Meetings with an advisory group were also used as a
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58 way to broaden influences on the study.
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Results

Participants described both positive and negative views of their prostheses, with some participants displaying a seemingly ambivalent relationship with their prosthesis, recognizing that it is helpful in some activities yet is *“more hassle than it is worth”* (Anna, aged 14) at other times. The following section describes two overarching themes – “Prosthesis as a help” and “Prosthesis as a hindrance”. Figure 1 shows the breakdown of themes into subthemes.

[Insert figure 1 here]

Theme one: “Prosthesis as a help”:

Participants described experiences where their prosthesis has been helpful to them for social interactions, when playing and for carrying out self-care and productive activities.

In social interactions

The participants described finding their prostheses useful in activities which involved an element of social interaction. The participants in the study used their prostheses to deal with unwanted attention in different settings, such as when at school and when out in public, particularly in situations where they would encounter people they did not know. Becky (aged 8) described how the assumptions people make about limb difference, and the things they say, 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.”

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3 The unwanted attention the participants described included staring, asking questions and
4 teasing:
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7 *“Say if I’ve had a bad day at school I normally wear it the next day. I don’t know why. Like,*
8 *people are teasing me or something”* (Becky, aged 8).
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13
14 Inherent in this desire to deflect unwanted attention was a feeling that the participants were
15 viewed by other people as “different” as a result of their limb difference, and that this could
16 cause embarrassment and isolation for them. Anna (aged 14), for example, remembered a
17 time when she was younger and was required to wear gloves as part of a costume:
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20
21 *“We had this dancing thing, where we had to wear, everyone had to wear, two blue gloves,*
22 *and so I had one, a cosmetic hand, so that I could wear two blue gloves as well. I was*
23 *embarrassed that everyone else had two and I only had one”.*
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33 Conversely, some participants reported choosing not to wear their prosthesis in social
34 situations because they found it led to more unwanted attention than when not wearing it. For
35 example,
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39 *“I think I feel more, not as much embarrassed, but more self-conscious if I do wear one [a*
40 *prosthesis], especially if I have short sleeves. Then I feel more self-conscious when I’m out*
41 *and about”* (Anna, aged 14).
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49 In play

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51 Another positive element of prosthesis use described by the participants in the study was
52 having fun with their prosthesis and using it in games with friends or for practical jokes, and
53 some of them even viewed it as a toy, storing it in their toy box. For example:
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3 *“For a joke at home I say to my sisters ‘you wanna piece of me? You wanna piece of me?’*
4 *and I take my [prosthetic] arm off and give it to them”* (Becky, aged 8).

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8 *“When we played games of tag, I used to use a prosthetic arm to actually tag the person or*
9 *grab their t-shirt”* (Gareth, aged 15).

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15 Using the prosthesis for play, fun and humour were also seen as a way of celebrating their
16
17 difference and appreciating something that is individual about them.

20 21 For self-care and productivity

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23 Participants talked about using their prostheses to increase their ability to perform functional
24
25 tasks. Some participants talked about using a prosthesis as a general aid for day-to-day tasks,
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28 whereas others talked about using one for specific activities.

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31 *“I used to use it for holding paper and stuff [...] It was useful when I was younger for cutting*
32 *and stuff”* (Lauren, aged 14).

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35 *“I might wear it if I was cleaning the bathroom because then I wouldn’t hurt my little arm*
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37 *when I’m cleaning or something like that”* (Emma, aged 9).

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42 Some participants talked about having prostheses that are specifically designed to aid with
43
44 particular activities that are important to them. Specific activities that the participants used
45
46 their prostheses for generally involved taking part in sports / Physical Education at school:

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49 *“When I play hockey it helps me hold my hockey stick because you have to have your right*
50 *arm at the bottom and I obviously can’t reach”* (Emma, aged 9).

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56 Participants appeared to find prostheses that were specifically designed for a task more useful
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58 for sports:
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3 *“I find the one that I’ve got at the moment, which I use for riding a bike, I find it really*
4 *helpful when I’m riding a bike because that’s the only thing I use it for”* (Chris, aged 12).
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10 As well as having prostheses for use specifically in sports, which included prostheses for
11 cricket, cycling, golf and press-ups, the participants talked about having prostheses to help
12 with typing and playing musical instruments:
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15 *“It’s a thing that goes on my arm so that I can attach a plectrum to it so that I can play the*
16 *guitar”* (Anna, aged 14).
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24 Participants described using their prostheses at times when they wanted to blend in and avoid
25 attention from others. However, at other times they were used to enhance play and humour
26 with friends. Prostheses were also seen to have practical functional benefit for some self-care
27 and productive activities, particularly when they had been designed for use specifically in
28 those activities.
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38 **Theme two: “Prosthesis as a hindrance”:**

39 Participants described choosing not to use prostheses as they found they provided no
40 functional benefit. In some instances (particularly sport) they were even reported to inhibit
41 participation and restrict the wearer’s range of movement.
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50 No functional benefit

51 Several of the participants reported having periods of not wearing a prosthesis because it did
52 not provide any functional benefit. Lauren (14) reported not using a prosthesis because it did
53 not help with activities:
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3 *“I used to wear it because I thought it would always help me with things but then after a*
4 *while I thought it’s not really helping me to do anything I couldn’t already. You can’t do*
5 *anything with it that you can’t do without it”.*
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10 11 12 In sporting activities

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14 Not only did the participants express the view that prostheses do not help function, but that
15 they can actually be a hindrance in certain activities or due to certain design features.
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19 *“You couldn’t hold the club because it was sliding around”* (Gareth, aged 15, talking about
20 playing golf).
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23
24 *“When you’re doing sports you always feel like you’re trailing it along [...] Just think it’d*
25 *kind of slow me down a bit. I wore it for football once but just kinda gave up after a while*
26 *just because [...] I just felt like I was trailing it around”* (Gareth, 15).
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33 In these instances, the participants were referring to trying to use general purpose passive or
34 body-powered prostheses for sports, rather than task-specific devices.
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38 39 40 Restricting movement

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42 Lauren (aged 14) talked about her prosthesis restricting her elbow movement:
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45 *“It blocks you from using your elbow so you can’t use it. So it’s there but you can’t do much*
46 *stuff with it [...] it was kind of blocking how to pick up things and stuff like that. I found it*
47 *made it harder a bit”.*
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53 The weight of the prosthesis, combined with limited movement, was also identified as a
54 factor in the prosthesis hindering function in daily tasks:
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3 “It was more hassle than it was worth because all it did was that [demonstrates opening and
4 closing of grip] and it was really heavy so it ended up being less convenient than without”
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8 (Lauren, aged 14).
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12 The results show prostheses will not be used if they do not provide some practical functional
13 benefit, particularly if issues with fit and weight result in restricted movement and difficulties
14 with participating in activities.
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19 20 21 *Discussion and implications* 22

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24 The participants in the current study evidently find prostheses useful at some times, and in
25 some activities, but a burden in others. Participants of the current study made much reference
26 to the responses of others to limb difference and the impact of this on prosthesis use. Being
27 viewed as different as a result of their impairment could result in feelings of embarrassment
28 and isolation for the participants, leading them to choose to use prostheses to blend in or
29 conform. Participants discussed finding their prostheses useful in social situations for
30 preventing unwanted attention. Conversely, they sometimes chose to not use their prostheses
31 when others around them accepted their differences, and the children and adolescents in our
32 study suggested that in these social contexts use of a prosthesis only highlighted their
33 differences. This reinforces the notion of disability being a socially constructed phenomenon
34 (Shakespeare and Watson, 2002), as unwanted attention is an extrinsic societal factor as
35 opposed to an impairment-based issue. The participants in our study chose whether or not to
36 wear their prostheses to conform to societal regulations rather than for making an activity
37 easier to perform, highlighting the prominence of socially constructed disability.
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3 Participants reported using their prostheses for self-care and productivity. They also
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5 described having fun with their prostheses and using them for play, which supports our
6
7 understanding of play as an important occupation for children (Case-Smith and O'Brien,
8
9 2015). Play is recognised as a central occupation of childhood, an essential part of children's
10
11 development (Larson 2004). It has been argued that play in childhood is equivalent to work in
12
13 adult life, in its capacity to encourage personal development and provide opportunities for
14
15 formative experiences (Ginsburg 2007). It is generally recognized that the two main functions
16
17 of a prosthesis are to improve a person's appearance and to increase their ability to perform
18
19 functional tasks (Spires et al., 2000). By directly exploring the views of children and
20
21 adolescents, however, it has been revealed that there is a third important function of
22
23 prostheses for this client group, which is as something to have fun with and include in play
24
25 with friends and family. It is interesting that, when with friends and family, participants
26
27 described using prostheses to enhance playful interactions, whereas with unfamiliar people
28
29 prostheses were used to conceal limb difference. Using prostheses in a fun and humorous
30
31 way may be an appropriate coping strategy for children and adolescents in managing stressful
32
33 events (Dowling 2002). It can enable them to view an upsetting or stressful event from a
34
35 different perspective and reappraise it as less threatening, lessening feelings of anxiety, fear,
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37 anger and frustration and helping them to gain control of the situation (Bennett 2003).
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47 In parallel to previous research by Wagner et al. (2007), several of the participants reported
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49 having periods of not wearing a prosthesis because it did not provide any functional benefit.
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51 Furthermore, they also reported finding them to be a hindrance in certain activities, due to
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53 design features or restriction of movement, with particular emphasis on the weight of
54
55 prostheses. This supports previous findings that prostheses do not always help function and
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3 are often too heavy for children (Biddiss and Chau, 2007; Pylatiuk et al., 2007; Routhier et
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5 al., 2001; Wagner et al., 2007).
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10 The prostheses that were described most positively by participants were those that had been
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12 designed for a specific use, rather than general purpose functional devices. This supports
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14 previous research that children and adolescents should be provided with prostheses to serve
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16 specific purposes and for use in particular activities so that they can select the device that will
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18 be most appropriate for the desired use (Buffart et al., 2007; Egermann et al., 2009; James et
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20 al., 2006). Prescribing general purpose functional prostheses implies the prosthesis is aimed
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22 at 'replacing' some function or cosmesis which is perceived to be 'lacking' or attempting to
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24 replicate a human hand. This strongly suggests an impairment-based approach to therapy,
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26 through treatment of the medical condition rather than adaptation of the social, cultural and
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28 environmental factors that may be leading to disability. Approaching prosthetic treatment as
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30 providing a 'replacement' for limb difference can be detrimental to ongoing rehabilitation
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32 and personal independence (Gallop, 2012). The current study suggests that prostheses as a
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34 general replacement for limb difference is largely unnecessary, with participants reporting
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36 that they feel comfortable with their difference and are able to complete their daily activities,
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38 as they have developed their own methods for performing the activities in a functional way.
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40 Our study suggests prescribing a device to assist with specific tasks may be more beneficial.
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Prosthesis development and prescription for children and adolescents may be more beneficial
if it focused on what they wish to gain from the use of a device (i.e. their activity goal) as
opposed to trying to 'treat' their 'deficiency' or replace the function they are (perceived to
be) lacking. By providing appropriate tools for completing particular activities (rather than a
general purpose prosthesis) emphasis is placed on adapting the physical demands of the
environment to enable a young person with limb difference to participate in the task.

Limitations

The findings have indicated that prostheses can be valuable tools for participation in occupations, although, due to the relatively small sample size, conclusions should be tentative. Furthermore, the environmental and task demands of performing these occupations require further study. An ethnographic study of prosthesis use in children's and adolescents' daily occupations could provide this insight.

Conclusion

Children and adolescents recognise that prostheses can serve particular functions for them and that they are useful in certain circumstances, but that prostheses may also have many drawbacks that counter the perceived benefits. Prostheses can be useful tools for occupational participation for children and adolescents providing that the right tool is provided for the task. Prescribing general purpose functional prostheses for children can result in the prosthesis not being useful or, worse, becoming a hindrance through restriction of movement and increased weight. Task specific devices can overcome these issues, as well as reflecting a less impairment-based approach to limb difference, which can be detrimental to developing independence.

Key messages

Key findings:

- Paediatric prostheses are used in social, productive and leisure occupations, including play;
- General purpose prostheses can be a hindrance in activities and represent an impairment-based approach to therapy;

- Task-specific devices can help to overcome some of these issues.

What the study has added:

Upper limb prostheses can be useful to children and adolescents for participating in occupations. However, they can also be a hindrance. Prosthesis prescription for children and adolescents should focus on what they wish to gain from the use of a device as opposed to trying to 'treat' their 'deficiency'.

Acknowledgements

We are grateful to the children and adolescents for their openness in sharing their experiences. We also want to thank Reach Charity Ltd for their support with recruitment, the members of the Advisory Board for their guidance, and the Child Prosthetics Research Group at Southampton University for their contributions to the wider project.

Research Ethics

Ethical approval was obtained from the University of Southampton's Faculty of Health Sciences' Ethics Committee (FoHS-ETHICS-2011-056; June 2011).

Consent

All participants provided written informed assent to be interviewed or participate in a focus group for the study. Their parents provided written informed consent for their children to participate.

Declaration of Conflicting Interests

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3 The author(s) declared no potential conflicts of interest with respect to the research,
4 authorship and publication of this article.
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10 **Funding**

11
12 The author(s) received no financial support for the research, authorship and publication of
13 this article.
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19 **Contributorship**

20
21 Tara Sims researched literature. All authors contributed to applying for ethical approval,
22 developing methodology and carrying out data collection. Tara Sims carried out the data
23 analysis. Tara Sims wrote the first draft of the manuscript. All authors reviewed and edited
24 the manuscript and approved the final version.
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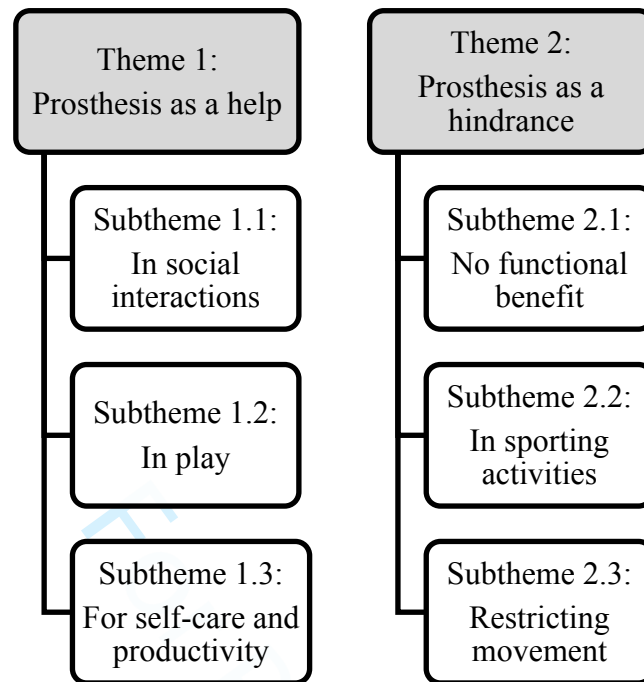
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17 *Table 1: Characteristics of participants*
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Participant (pseudonym)	Gender	Age	Aetiology	Side of limb difference	Experience of prosthesis use (daily, occasional, previous)	Part of UK
Becky	Female	8	Congenital	Left	Occasional	England
Anna	Female	14	Congenital	Left	Occasional	England
Gareth	Male	15	Congenital	Right	Previous	Scotland
Lauren	Female	14	Congenital	Right	Previous	Wales
Emma	Female	9	Congenital	Right	Previous	England
Chris	Male	12	Acquired	Right	Previous	England
David	Male	10	Congenital	Right	Daily	England
James	Male	8	Congenital	Left	Daily	England

Figure 1: Themes and subthemes



Appendix: Questioning Route for interviews and focus group

For inclusion in focus group, interview or both	
Focus Group	<p>Opening Questions</p> <ul style="list-style-type: none"> • Tell us your name and where you live • Tell us your first name and your favourite colour
Both	<p>Introductory Questions</p> <ul style="list-style-type: none"> • Think about the first prosthetic arm you can remember having, what was it like? <ul style="list-style-type: none"> • What were the things you liked about it?

	<ul style="list-style-type: none"> • What were the things you didn't like about it?
Both	<p>Transition Questions</p> <ul style="list-style-type: none"> • What has been the best prosthetic arm you've had? – What made it the best? • Thinking about all the different prosthetic arms you've had... <ul style="list-style-type: none"> • What's been good or bad about the way they've looked? • What's been good or bad about the things you could use them for/what you could do with them? • What's been good or bad about the way they felt? • Were they comfortable? What did or didn't help them to be comfortable?
Both	<p>Key Questions</p> <ul style="list-style-type: none"> • I want you to imagine that I have a magic wand and can conjure up your ideal prosthetic arm: <ul style="list-style-type: none"> • What would it look like? <ul style="list-style-type: none"> • Colour • Special features • Feel/texture of the surface • What activities would it help you to do? <ul style="list-style-type: none"> • at home

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	<ul style="list-style-type: none"> • at school • with friends • How would you feel about it? • What would other people think about it? • How would it feel when you're wearing it?
Interview	<p>Ending Questions</p> <ul style="list-style-type: none"> • Is there anything else that we haven't already talked about that you would like to tell me about?
Focus	<ul style="list-style-type: none"> • Is there anything else that we haven't already talked about
Group	<p>that anyone would like to add about their ideal prosthetic UL?</p>

For Peer Review

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