

A literature review of children's use of and satisfaction with upper limb prostheses.

Dr Tara Sims

Senior Lecturer in Occupational Therapy

School of Health Sciences, University of Brighton.

Abstract

Non-use rates of upper limb prostheses amongst children have, in some studies, been reported to be as high as 50%. This literature review aims to examine why non-use of prostheses is so high amongst children through synthesising research that examines their use of, and satisfaction with, prosthetic devices. A search of the literature was conducted in July 2017 using the Allied and Complementary Medicine Database (AMED), the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MedLine, PsychArticles and PsychInfo. Eight articles relevant to the current review were identified and citation searching provided a further two relevant studies. Studies relating to children's use of prostheses highlighted that they find task-specific prosthetic devices more useful than general purpose prostheses, as they are able to select the appropriate device for the desired use. Studies related to children's satisfaction with prostheses identified that they are dissatisfied with prostheses' appearance, comfort, weight, heat, freedom of movement function, ease of control, reliability and cost.

Introduction

Limb difference in children can be the result of congenital factors or acquired amputation (Smith, 2006). A congenital limb deficiency is present at birth and can involve either the upper or lower limb or, in rare instances, multiple limbs (Smith, 2006). Acquired amputations can be the result of cancer, trauma or severe infections, such as meningococcal septicaemia (Smith, 2006).

Congenital upper limb difference can range from the partial loss of a finger, to the complete loss of both arms (Broomfield, 2009). Broomfield (2009) suggests that approximately 60 children are born with congenital limb difference annually in the UK. There are however no published statistics on this.

The upper limb accounts for between 3% to 15% of all amputations across adults and children (Jain and Robinson, 2008). However, this figure applies across all ages, giving us little indication of the actual percentage for children. The major reasons for amputation in the upper limb, again not accounting for age differences, are trauma (43%), congenital absence (18%), and cancer (14%) (Jain and Robinson 2008).

In 2006-2007, 4957 new referrals were made to UK prosthetics service centres (Limbless Statistics, 2009). Of these, 163 were less than 16 years old. Of these 163, 87 were referred to prosthetics services due to congenital absence and 76 following traumatic limb loss. Upper limb difference accounted for approximately 4% of all referrals across adults and children (approximately 198). However, upper limb referrals were more common in younger people. Approximately 60% of all referrals with a congenital absence were aged less than 16 years of age. There is no

information reported on Limbless Statistics (2009) regarding the numbers of under 18 year olds who are active patients of UK limb services, as the reported statistics only relate to new referrals. Although the percentage of new referrals relating to children with an upper limb difference is small (3%), these service users will require the support of limb services for a longer time frame than adult users (Limbless statistics 2009). The College of Occupational Therapists (COT) (2006) reports that the number of upper limb amputees and limb deficient children, when examining 'active' files at limb fitting centres, is approximately 20% of service users.

Non-use rates of upper limb prostheses amongst children vary widely throughout the literature but they have, in some studies, been reported to be as high as 50% (Shida-Tokeshi et al., 2005). This literature review aims to examine why non-use of prostheses is so high amongst children and young people through synthesising research that relates to their use of, and satisfaction with, devices.

Methods

A search of the literature was conducted in July 2017. The databases searched were the Allied and Complementary Medicine Database (AMED), the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MedLine, PsychArticles and PsychInfo. The search terms used were prosthesis (and alternatives), upper limb (and alternatives) and child (and alternatives). A Boolean search was performed using search devices such as 'wildcards' when appropriate to the database. In addition to these searches, reference lists in relevant articles were hand searched for other relevant research and forward citation searching was performed using Web of Knowledge. Publication dates were restricted to 2000 onwards to ensure findings are

relevant to current practice and to English language only to avoid mistakes being made in the translation of documents.

Results

Scrutiny of the articles obtained from the literature search resulted in the identification of eight articles relevant to the current review. Citation searching provided a further two relevant studies.

Articles relevant for this literature review identified through literature search = 8

- Children's use of prostheses = 3
- Children's satisfaction with prostheses = 4
- Both = 1

Articles identified via citation searching = 2

Total number of articles = 10

Children's use of prostheses

Five relevant articles were found in relation to children's use of prostheses. Two of the studies were conducted in America and three in Europe. One of the articles related to both children's use of and satisfaction with prostheses (Vasluian et al., 2015). These articles are discussed in the following section.

1. Vasluian et al (2015) Carried out a questionnaire study of 218 children and adolescents (aged 2-20 years) with upper limb difference and their parents to examine children's use of, and satisfaction with, prostheses and other assistive devices (such as adapted cutlery). They found that, whilst prostheses were used for self-care, mobility, communication, leisure and productive activities, they were only used by a minority of participants.

Completing activities without the use of any equipment or with assistive devices other than prostheses was much more common. They suggested that children and adolescents may find assistive devices, and alternative methods for completing tasks, more useful than prostheses.

2. Egermann et al (2009) carried out a retrospective study, in Germany, of myoelectric prosthesis use with 41 children aged less than six years. **A myoelectric prosthesis uses electromyographic signals from voluntarily contracted muscles within a person's residual limb to control the movements of the prosthesis (Egermann et al., 2009). Myoelectric prostheses combine aesthetics and functionality as they can have cosmeses, which have the appearance of a real hand, as well as providing functional movement for use in activities of daily living (Egermann et al., 2009).** The families of prosthesis users completed a questionnaire exploring the child's use of their prosthesis in everyday activities, such as playing indoors and outdoors and at Kindergarten. The authors considered prosthesis use of more than two hours a day as a 'successful' use of the prosthesis and found that 76% of the participants were using their prosthesis 'successfully'. They found that the children preferred to use their prosthesis for indoor as opposed to outdoor play, which may be related to the feedback from the participants that the technical reliability of the prosthesis was unsatisfactory and that it was prone to breaking down. The authors concluded that the poor durability of the myoelectric prosthesis reduces its compatibility with certain child-centred occupations, such as outdoor play. They suggested, therefore, that children should be provided with a range of prosthetic options so that they can change

their prosthesis throughout the course of a day in order to select the most appropriate device for the task or environment.

3. Buffart et al (2007) carried out a study, in the Netherlands, of 20 children (aged 4-12 years old) with congenital upper limb difference. The study combined observational assessments of functional activities with parent-report questionnaires focusing on daily activities. They found that children were able to use their prostheses in 68% of activities but chose to use them in only 30%. Furthermore, whilst the prosthesis was rated by only 37.5% to be useful for general use, when specific activities were considered (such as using scissors or riding a bicycle) the usefulness of the prosthesis rose to 75%. They concluded from this that children may wish to use prostheses for specific activities, rather than for general daily activities, and that prosthesis prescription should take this into consideration.
4. James et al (2006) examined prosthesis use in 489 children and adolescents (aged 2-20 years old) attending the Shriners Hospital in California, USA. They used five standardised tests to explore a range of factors related to prosthesis use. Some of the tests were administered to the children and others to their parents. They found that prosthesis use did not influence functional ability and that non-wearers of upper limb prostheses performed just as well, or even better than their prosthesis-wearing peers. These findings may suggest that although prostheses may not improve function, they may serve other purposes for children and young people, such as promoting social acceptance and for use as a tool for specific activities.
5. Crandall & Tomhave (2002) used questionnaires to explore prosthesis use in 34 paediatric unilateral below elbow amputees (aged from 6 to 21 years old),

attending the Shriners Hospital in Minneapolis, USA. They found that 44% of participants used a passive device, 41% used a body-powered prosthesis and 41% used multiple devices. The authors concluded that children may choose to use different devices depending on the intended use, and that they should, therefore, be offered a range of prosthetic options to enable them to carry out daily activities to their optimum potential.

Children's satisfaction with prostheses

Six studies relating to children's satisfaction with prostheses were identified. Three of the studies were conducted in America and three in Europe. One of the studies related to both children's use of and satisfaction with prostheses (Vasluian et al., 2015). The studies will be discussed in the following section.

1. Vasluian et al (2015) carried out a questionnaire study of 218 children and adolescents (aged 2-20 years) with upper limb difference and their parents to examine children's use of, and satisfaction with, prostheses and other assistive devices. They found that children were more satisfied with task-specific assistive devices than with prostheses. They suggested that assistive devices are good alternatives to prostheses.
2. The Our Bodies Our Views project (Donovan-Hall, 2010) encompassed several studies exploring children's views of prostheses, which involved a three phase mixed-methods programme of research. This included using a questionnaire with both closed and open questions to examine children's views about upper and lower limb prostheses. The questionnaire examined how satisfied participants were with their prosthesis (if they wore one), what

aspects of the prosthesis were important to them and reasons for not wearing a prosthesis. The appearance and function of prostheses were found to be very important to 70% of the participants, and nearly 90% of participants indicated that being involved in choosing the prosthesis was important to them. Open questions about reasons for not wearing a prosthesis revealed the following contributing factors: the comfort of the prosthesis (including being itchy/irritating, hot/sweaty, too heavy and painful); managing better without a prosthesis and issues relating to appearance (such as, it gets dirty and draws attention from others). Donovan-Hall (2010) also used interviews to explore the views of children and young people (aged 11 to 18 years) on prostheses. The participants included 11 males and 10 females who had upper or lower limb difference. The main issues found to be of importance were appearance, comfort and weight. For a number of participants, the appearance of the prosthesis influenced their satisfaction with the prosthesis and the majority wanted their prosthesis to be lifelike in appearance so that it would be less noticeable to others. Comfort also influenced satisfaction with the prosthesis with participants reporting that the prosthesis could often be hot and sweaty to wear. Issues related to the function of the prosthesis seemed to mainly refer to the durability of prostheses and the desire to have prostheses that would last for a long period of time. Participants described how the cosmesis could become stained quite quickly or parts of the prosthesis could become loose and break.

3. Biddiss & Chau (2007) explored users' satisfaction with their prosthesis using mixed methods. They used an online questionnaire, with both open and closed questions, to collect information on demographics, experience of limb

difference, activities of daily living (ADLs), prosthesis use and prosthesis satisfaction. The questionnaire was completed by 242 participants over the age of 12 and with all levels of limb difference from across the USA, Canada and the Netherlands. Parents were requested to complete the questionnaire on behalf of any children under the age of 12 as it was deemed too complex for children below this age. The researchers found that those who rejected their prosthesis were dissatisfied in the areas of appearance, comfort, function, ease of control, reliability and cost.

4. Pylatiuk et al (2007) conducted an internet survey of 54 German users of myoelectric prostheses, which included 11 child participants (aged 14 or under). The survey was either completed by the child or their parent(s). The survey asked the participants to rate their prosthesis on noise, weight and cosmetic appearance using a Likert scale. They found that all of the child participants rated the weight of their prosthesis as either a little or much too high. The survey also presented participants with a list of activities they may wish to perform with their prosthesis and found that 83% of children wanted to be able to use their prosthesis for personal hygiene, using cutlery and dressing/undressing.
5. Wagner et al (2007) carried out research with 168 children with unilateral congenital transverse forearm total deficiency (UCTFTD), who had attended prosthetic rehabilitation clinics in the USA and Canada, and who did not wear a prosthesis. Parents were asked to answer (on behalf of their children) "What are the reasons for not wearing a prosthesis?" Their findings indicated that dissatisfaction with the prosthesis was related to choosing not to wear a

prosthesis. The two most common reasons given were the prosthesis does not help function (53%) and the prosthesis is uncomfortable (49%).

6. Routhier et al (2001) used a quantitative approach to examine satisfaction of 18 Canadian children who used an upper limb myoelectric prosthesis in order to identify which factors influenced the use or non-use of a device. They used the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers et al 1996) to assess the degree to which the children were satisfied with their prostheses. The QUEST (Demers et al 1996) explores the importance that participants attribute to different aspects of their prosthesis and rates their degree of satisfaction with each of these attributes using a 5-point Likert scale. The most important variables identified by the children were: weight, comfort, effectiveness, appearance, simplicity of use and training. More than half of the participants reported that they were not satisfied with the heat, weight, comfort and freedom of movement provided by their prosthesis. They also reported issues with lack of wrist rotation and loss of tactile sensation.

Discussion

Studies relating to prosthesis use:

Definitions of “prosthetic use” in the literature include both the activities that a person finds a prosthesis helpful for and the amount of time a person uses a prosthesis for (Hubbard-Winkler, 2009). Furthermore, the amount of time a person uses a prosthesis for is measured in some studies on a continuous scale and in others using a categorical scale (such as, whether the prosthesis is worn, “all the time”, “occasionally” etc.) (Hubbard-Winkler, 2009). Even when looking separately at either

continuous or categorical measurement studies, measurement is not standardised and may relate to different types of prostheses, which often goes unstated (Hubbard-Winkler, 2009). This makes it difficult to develop an understanding of how, when and why prostheses are used by children and young people.

The studies discussed in this review may all be using different operational definitions of “prosthesis use” and not all the studies clearly state what definition they are using. It is also worth noting that the countries in which the research was conducted (USA, Germany and the Netherlands) have different healthcare systems, which all differ from the NHS in the UK, and have different degrees of government and private funding. The different funding methods may have implications for the devices that are issued and the way services are delivered. This can pose difficulties when combining or collating their findings to draw conclusions. Furthermore, the studies largely depend on collection of data in the form of a questionnaire completed by the children’s families. The results collected, in terms of prosthetic use will, therefore, inevitably have an adult influence due to using adult proxies to gain the children’s perspectives. Despite these methodological drawbacks, these studies all engender the same conclusions: 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.

Heard et al (1994) demonstrated that a full-time wearer is not necessarily a full-time user. It is possible to wear a prosthesis without using it as a tool. Children do not necessarily wear their prostheses to complete ADLs as they will only do so if the activities are performed more easily or quickly (Heard et al., 1994). However, for

many bimanual tasks, such as riding a bicycle or using scissors, it is necessary to use both hands, and, consequently, the prosthesis (Heard et al., 1994). Children and adolescents may, therefore, benefit from being able to choose their prosthesis based on the needs of the activity they require it for, calling in to question the prescription of general use functional prostheses for young people. The use of a prosthesis may be better measured through consideration of the activities it is useful for, and the value the individual places on completing these activities independently, as opposed to wearing time.

Studies relating to prosthetic satisfaction:

“Satisfaction” within studies of prostheses has been used to refer to satisfaction with the ability to perform specific activities, overall satisfaction with the prosthesis and satisfaction with the individual characteristics of the prosthesis (Hubbard-Winkler, 2009). The studies discussed in this review use different operational definitions for these terms.

Some of the studies discussed used parent proxy reports to explore the views of children, which may raise questions about the truthfulness of the results obtained: Sheffler et al (2009) compared self-report with parent proxy report of function and quality of life amongst children with limb difference and found that parents underestimated their child’s physical function and overestimated their comfort. However, common to the studies discussed, was the finding that children are dissatisfied with many aspects of upper limb prostheses, including appearance, comfort, weight, heat, freedom of movement, function, ease of control, reliability and cost.

Conclusion

Despite issues with lack of consistency of operational definitions for the terms used in the research on children's use of and satisfaction with upper limb prostheses, and some drawbacks to the methodologies employed, looking at the body of evidence as a whole provides some useful considerations when working with children with limb difference:

- Children find task-specific prosthetic devices more useful than general purpose prostheses, as they enable them to select the appropriate device for the desired use.
- Attributes of prostheses, such as appearance, comfort, weight, heat, freedom of movement, function, ease of control, reliability and cost are important considerations when prescribing prostheses as they may impact on children's satisfaction with the device.

Occupational therapists working with children with limb difference should maintain an occupational focus to assessment in order to identify the child's needs and wants in terms of their activity participation. In order to maintain an occupation-focused approach to assessment it may be most appropriate to begin with an individualised measure to first identify priority areas for intervention for the child. Occupational therapists must also have the confidence to recognise that prosthetic management is not always the best treatment for children and young people. Other interventions, such as adaptive devices, adapting tasks/environments or finding alternative ways of completing activities can then be explored.

References

Biddiss EA & Chau TT (2007) Upper limb prosthetics, critical factors in device abandonment. *American Journal of Physical Medicine and Rehabilitation*, 86(12): 977-87.

Broomfield M (2009) *Guide to Artificial Limbs*. Available from: <http://www.reach.org.uk/ReachCMS/assetmanager/images/files/guidetoartificialarms.pdf> (Accessed 23/03/2017).

Buffart LM, Roebroek ME, van Heijningen VG, Pesch-Batenburg JM and Stam HJ (2007) Evaluation of arm and prosthetic functioning in children with a congenital transverse reduction deficiency of the upper limb. *Journal of rehabilitation Medicine*, 39(5): 379-386.

College of Occupational Therapists (2006) *Upper Limb Prosthetic Rehabilitation*. London: College of Occupational Therapists.

Crandall RC and Tomhave W (2002) Paediatric unilateral below-elbow amputees: retrospective analysis of 34 patients given multiple prosthetic options. *Journal of Paediatric Orthopaedics*, 22(3): 380-383.

Donovan-Hall M (2010) *Supporting the positive development and well-being of children and young people with prostheses: the influence of the appearance of the prosthesis and individual choice*. Big Lottery Final Report (RG1/010120846).

Egermann M, Kasten P and Thomsen M (2009) Myoelectric hand prostheses in very young children. *International Orthopaedic*, 33(4): 1101-1105.

Heard DCY, Atkins DJ and William HD (1994) Priorities for improving myoelectric prostheses as defined by the child and their parents. *Proceedings of the UNB's Myoelectric Controls/Powered Prosthetics Course and Symposium*.

Hubbard-Winkler SL (2009) Upper limb amputation and prosthetics epidemiology, evidence, and outcomes. In: Pasquina PF and Cooper RA (Eds.) *Care of the combat amputee*. Washington (DC): Borden Institute.

Jain AS and Robinson DP (2008) *Synopsis of Causation: Upper Limb Amputation*. USA: Ministry of Defence.

James MA, Bagley AM, Brasington K, Lutz C, McConnell S and Molitor F (2006) Impact of Prostheses on Function and Quality of Life for Children with Unilateral Congenital Below-the-Elbow Deficiency. *The Journal of Bone and Joint Surgery*, 88(11): 2356–2365.

Limbless Statistics (2009) The Amputee Statistical Database for the United Kingdom 2006/07. Edinburgh: Information Services Division NHS Scotland.

McDonnell PM, Eng SP and McKay A (1988) Incidence of Congenital Upper-Limb Deficiencies. *JACPOC*, 23(1): 8.

Pylatiuk C, Schulz S and Doderlein L (2007) Results of an Internet survey of myoelectric prosthetic hand users. *Prosthetics and Orthotics International*, 31(4): 362-70.

Routhier F, Vincent C, Morissette MJ and Desaulniers L (2001) Clinical results of an investigation of paediatric upper limb myoelectric prosthesis fitting at the Quebec Rehabilitation Institute. *Prosthetics and Orthotics International*, 25(2): 119-131.

Sheffler LC, Hanley C, Bagley A, Molitor F and James MA (2009) Comparison of Self-Reports and Parent Proxy-Reports of Function and Quality of Life of Children with Below-the-Elbow Deficiency. *Journal of Bone and Joint Surgery*, 91: 2852-2859.

Shida-Tokeshi J, Bagley A, Molitor F, Tomhave W, Liberatore J, Brasington K and Montpetit K (2005) Predictors of Continued Prosthetic Wear in Children With Upper Extremity Prostheses. *Journal of Prosthetics and Orthotics*, 17(4): 119-124.

Smith DJ (2006) Congenital Limb Deficiencies and Acquired Amputations in Childhood Part 3. *In Motion*, 16(3).

Vasluian E, van Wijk I, Dijkstra PU, Reinders-Messelink HA and van der Sluis CK (2015) Adaptive devices in young people with upper limb reduction deficiencies: Use and satisfaction. *Journal of Rehabilitation Medicine*, 47(4): 346-355.

Wagner LV, Bagley AM and James MA (2007) Reasons for prosthetic rejection by children with unilateral congenital transverse forearm total deficiency. *Journal of Prosthetics and Orthotics*, 19(2): 51-54.