

Reasons for Prosthetic Rejection by Children With Unilateral Congenital Transverse Forearm Total Deficiency

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ABSTRACT

As many as half of children with unilateral congenital transverse forearm total deficiency (UCTFTD) choose not to wear a prosthesis. In a multicenter study, 489 children and young adults aged 2 to 20 years with UCTFTD and their parents were tested for satisfaction, quality of life, and function. One hundred sixty-eight (34%) of those tested had chosen not to wear a prosthesis. Subjects and parents were asked the open-ended question "What are the reasons for not wearing a prosthesis?" and were allowed to give more than one response. Of the 135 subjects who had chosen not to wear a prosthesis and who responded to the question, the reason most frequently (53%) given was that the prosthesis did not help function. Forty-nine percent reported they stopped wearing it because the prosthesis was uncomfortable. Currently, upper-extremity prosthetic management for children with UCTFTD is a matter of controversy, with some clinicians advocating the need for prostheses to accomplish bilateral hand tasks, particularly in the scheme of normal development. Responses from children who do not wear a prosthesis may aid practitioners in re-evaluating the prosthetic role and potentially improve prosthetic options. (*J Prosthet Orthot.* 2007;19:51-54.)

KEY INDEXING TERMS: comfort, function, prosthesis, rejection, satisfaction

Prosthesis rejection rates range from 10% to 49% in the pediatric population.¹⁻⁴ To optimize the function of children with unilateral congenital transverse forearm total deficiency (UCTFTD), it would be useful to document why patients reject or choose not to wear a prosthesis. The focus of previous studies of prosthetic rejection has been on the actual prosthetic device. For all upper-limb deficiencies, Kejlaa⁵ reports that overall cessation of prosthetic use was related to prosthetic problems in 4 of 18 cases (22%). Clients wearing a body-powered (BP) prosthesis report that the harness is uncomfortable and breaks often, and that there are limits in the style of clothing that can be worn with the cabling system. Additional issues were skin irritation, overall heat and heaviness of the prosthesis, and cosmetic concerns.⁵⁻⁷ With the advent of the myoelectric prosthesis, attempts were made to address the complaints of harnessing and appearance; however, disadvantages also were found with this style of prosthesis. In the literature from the 1990s,⁵⁻⁷ it is reported that myoelectric prostheses are heavy, noisy in operation, and require more maintenance than do BP devices, although current models may not have these problems. In

addition, it is difficult to keep the glove clean, and the batteries need to be recharged regularly. Even the lightweight passive prosthesis, a recommendation for many children, has limitations. It is hot, and the gloves are difficult to keep clean.⁵

Looking beyond individual prosthetic prescription concerns, the literature records overall dissatisfaction with the functional abilities of upper-limb prostheses. Postema et al.⁸ report that lack of functional gain was the leading response given by both parents and children for rejection of a prosthesis. Burrough and Brook⁹ confirm this by stating there is dissatisfaction with the number of activities that can be performed with the prosthesis and with standards of performance that can be reached. In a study of the same population, James et al.¹⁰ report that children with UCTFTD exhibit high function and quality of life, regardless of wearing a prosthesis.

Although the reasons for rejection of upper-limb prostheses would appear to apply to the UCTFTD population, seven of the nine articles referenced evaluated all levels of upper-limb deficiencies. Postema et al.⁸ and James et al.¹⁰ focus on children with a unilateral congenital arm defect, whereas all the other authors include subjects with both traumatic and congenital deficiencies.

What are the reasons for rejection of a prosthesis in the UCTFTD population? Are the reasons consistent with those of the overall upper-limb deficiency population? The current study reviews the responses given in the UCTFTD population for prosthetic rejection. With reasons for rejection properly documented, improvements in prosthetic design, prescription, and training may be achieved, or a paradigm shift away from routine prescription of a prosthesis in the UCTFTD population may be recommended.

METHODS

Ten Shriners Hospitals for Children from the United States and Canada participated in a multicenter cross-

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Table 1. Demographic information for nonwearer children and young adults with UCTFTD

	Not Wearing Now		Never Wore	
	Number	Percent	Number	Percent
Gender				
Male	71	52	13	42
Female	66	48	18	58
Affected side				
Left	80	58	23	74
Right	57	42	8	26
Age				
2 to 4 y	16	12	17	55
5 to 7 y	34	25	7	22
8 to 10 y	22	16	3	10
11 to 19 y	65	47	4	13
Total	137		31	

sectional study of 489 subjects, ages 2 to 20 years, with UCTFTD. The sample included both prosthesis wearers and nonwearers. Nonwearers were defined as not having worn a prosthesis for at least the previous 6 months. These children and young adults, with their parents, participated in a testing protocol established by the Unilateral Congenital Below Elbow Deficiency Study Group. The protocol consisted of a demographic questionnaire with a specific question regarding reasons for rejection of a prosthesis, five computerized questionnaires assessing prosthetic satisfaction (for prosthesis wearers only), quality of life, musculoskeletal health and satisfaction, functional status, and one videotaped functional evaluation. All data were entered into a comprehensive database, and statistical analyses were performed on the entire population.

Thirty-four percent (168/489) of the total population did not wear a prosthesis. Of the 168 nonwearers, 137 had worn a prosthesis at some time but had abandoned wear at the time of the study, and 31 had never worn a prosthesis. The demographics for these subjects are reported in Table 1.

One hundred thirty-five of the 168 nonwearers reported reasons for not wearing a prosthesis. Of those 135 clients, 24 had never worn a prosthesis. The ages of the subjects responding were from 2 to 19 years.

The question regarding prosthetic rejection was “What are the reasons for not wearing a prosthesis?” There were eight response options available, including “other” and a space for comments (Table 2). The instructions for this question stated “Check all that apply,” so there were 282 responses for the 135 clients. The frequencies of responses were recorded, and additional comments were grouped by topic.

RESULTS

Data from 110 of the subjects who had abandoned prosthesis use showed that 58% had been fit before 1 year of age, and an additional 18% had been fit between 1 and 2 years of

Table 2. Demographic questionnaire response options

Prosthesis didn't help function
Prosthesis was uncomfortable
Parents didn't like appearance
Child didn't like appearance
Child was teased
Prosthesis maintenance, fitting, and/or clinic appointments too burdensome
Prosthesis had poor fit
Other (specify)

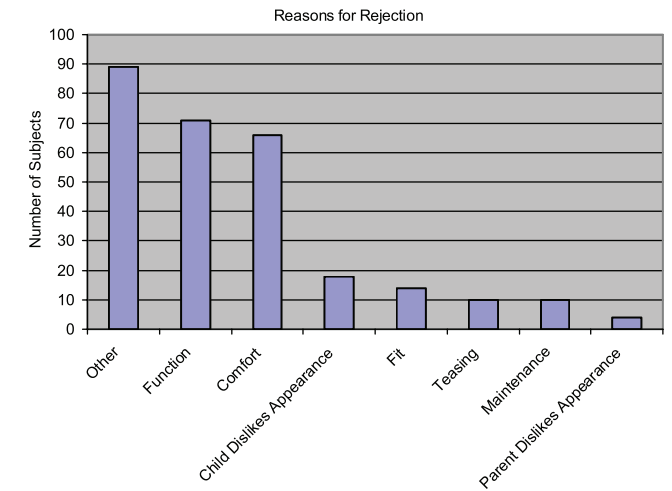


Figure 1. Reasons for rejection of a prosthesis given by parents and children.

age. Sixty-five percent had received a passive prosthesis, and 25% had received a BP prosthesis as their first device. Seventy percent had received prosthetic training. Thirty-seven percent stopped wearing the prosthesis between 1 and 5 years of age, 36% stopped wearing between 5 and 10 years of age, and 19% stopped wearing between 10 and 15 years of age.

The results from the prosthetic rejection question are presented from greatest to least frequency in Figure 1 and are described in greater detail here.

OTHER

Eighty-nine “other” responses (32% of the total number of responses) were given by 85 (63%) subjects. Many of these comments were clarification of a previously checked response and are described within the specific response section. Additional comments included: no opportunity to wear a prosthesis; no sensation in the residual limb with prosthesis on; skin problems; and visa problems (residents of Mexico traveling to the United States for care). Thirteen miscellaneous responses could not be grouped into categories. These included comments such as prosthesis drew attention to the child; they did not like the battery sound (sound of the motor); parents were too lazy; and the training they received was poor (Figure 2).

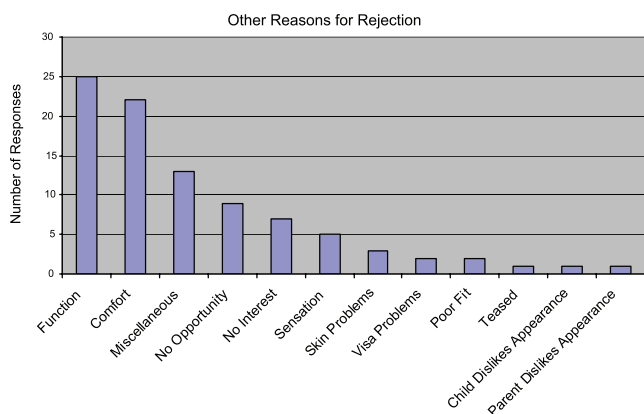


Figure 2. The number and type of other responses given by parents and children.

PROSTHESIS DIDN'T HELP FUNCTION

This specific response was chosen by 71 (53%) subjects. "Other" comments grouped in this category included there was no need for a prosthesis; the clients found they could do well without a prosthesis; the prosthesis got in their way; and they could not drive while wearing the prosthesis.

PROSTHESIS WAS UNCOMFORTABLE

This specific response was chosen by 66 (49%) subjects. "Other" comments grouped in this category included the prosthesis was too hot, sweaty, or heavy; it was uncomfortable in every way; and the harness was uncomfortable.

CHILD DID NOT LIKE APPEARANCE OF PROSTHESIS

This specific response was chosen by 18 (13%) subjects. The "other" response given was that the prosthesis was too long.

PROSTHESIS HAD POOR FIT

This specific response was chosen by 14 (10%) subjects. The "other" responses given were the client outgrew the prosthesis and it was difficult to get a good fit.

CHILD WAS TEASED

This specific response was chosen by 10 (7%) subjects. The "other" response given in this category was that it was hard to go to school and be a normal kid.

PROSTHESIS MAINTENANCE, FITTING, AND/OR CLINIC APPOINTMENTS TOO BURDENSOME

This specific response was chosen by 10 (7%) subjects. The "other" responses given were harnessing problems and family illness.

PARENT DID NOT LIKE APPEARANCE OF PROSTHESIS

This specific response was chosen by four (3%) subjects. The "other" response given for this category was the desire to have the arm look more life-like.

DISCUSSION

The principal reasons for rejection of a prosthesis were lack of function, including some cases in which the device impaired function, and lack of comfort. The literature from the wider population of upper-limb deficiencies (e.g., including adult and traumatic and above-elbow subjects) supports these findings. Routhier et al.¹¹ comment that a child will wear a prosthesis only if it is useful; if the prosthesis is not functional, the prosthesis will be discarded. This current study supports this logic. Children with congenital transverse forearm total deficiency reported the primary reason for rejection was a lack of function. This evidence also supports the conclusions of Sudesh¹² and Kuyper et al.¹³ that children with congenital deficiencies have no sense of loss and develop compensatory skills for bimanual tasks. Results of standardized functional tests show that children with UCTFTD do not demonstrate functional deficits in daily activities.¹⁰

Because children develop compensatory skills and 90% of all activities of daily living (ADL) skills can be performed with only one hand,¹⁴ the primary focus for fitting a prosthesis should not be the need for function for daily activities, but rather as a tool to assist with the performance of specific tasks. Of the 27 responses from children who had never worn a prosthesis, 9 comments referred to the subjects having no desire for a prosthesis or to their functioning well without a prosthesis. Melendez and LeBlanc¹⁵ report that unilateral arm amputees who choose not to wear a prosthesis consider themselves to be functional and independent.

This article attempts to express the client's perspective of prosthetic rejection and does not explore other factors that may contribute to nonwear, such as age of first fit, style of prosthesis prescribed, and exposure to training. In this study, most of the children who had abandoned prosthetic use had been fit at less than 1 year of age, had been first prescribed a passive prosthesis, and had received training, in accordance with current clinical practice beliefs. Additional analysis of the data from the entire population of 489 children with UCTFTD (wearers and nonwearers) will focus on prosthetic wearing as it relates to age of first fitting, training, and wear time.

Another limitation of this study is that only a general question regarding reasons for rejection was asked. When answering this question, many responders may have focused on basic activities of daily living or general tasks, not contemplating more involved activities or skills they do not regularly perform because of their limb deficiency. It is possible that evaluating prosthetic needs through more specific participation measures, such as hobbies and sports and leisure activities, may help to identify specific activities that

require prosthetic assistance for two-handed function. Melendez and LeBlanc¹⁵ challenge the clinic team to “consider all options for promoting function, and not to confine intervention to prosthetic fitting alone.” The results of this article and the literature cited in this article encourage clinicians to embrace this challenge and create assistive devices, adaptive equipment, and prostheses that benefit children with UCTFTD in ways they can perceive.

Feedback from prosthetic wearers can be used to promote advancements as the prosthetic industry continuously seeks to improve the available options for upper-extremity devices. Addressing the need for increased function, researchers are developing prostheses that provide a variety of grasps¹⁶ and terminal devices that respond with increased speed.¹⁷ New technology for options to activate a prosthesis are being explored in the areas of mechanomyography¹⁸ and targeted motor reinnervation.¹⁹ Upper-extremity comfort is being addressed through roll-on suction suspension liners and friction-free donning socks.¹⁷ The introduction of hydraulic systems may decrease the prosthetic weight by 50% as compared with conventional hands.¹⁶

As research and development in the field of upper-extremity prosthetics continues to grow, the future for prosthetic development and increased use is encouraging. The tragic increase in upper-extremity deficiencies associated with the Iraq war is stimulating some exciting research in this field, and results are making their way to publication. In addition, clinicians should consider the evidence that function and quality of life in children with UCTFTD are not impaired for those who choose not to wear a prosthesis. For those who choose a prosthesis, prostheses can offer enhancements to various occupational performance activities. Upon acknowledgment of the concerns of amputees regarding prostheses, the continual improvements in prosthetics should enhance the acceptance of prostheses for various activities.

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