

## Experiences of the use of 3D printed hand ortoprosthesis (Cyborg Beast) in adolescents with congenital hand amputation and their main caregivers: A study of cases

### Experiencias del uso de ortoprótesis de mano impresa en 3D (Cyborg Beast) en adolescentes con amputación congénita de mano y sus cuidadores principales: Un estudio de casos

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#### Abstract

**Objective:** To describe the experience of using the 3D-printed prosthetic hand Cyborg Beast in adolescents of Teletón Santiago with congenital hand amputation and their main caregivers who participated in a case study to evaluate the functionality of the prosthetic hand. **Clinical Case:** Qualitative and descriptive research of case studies using semi-structured interviews with five adolescents with congenital hand amputation and their main caregivers. The information was transcribed and analyzed through open coding. Participants visualize the prosthesis as an opportunity for them by associating it with normality. They also identify positive and negative characteristics, emphasizing in the latter. In addition, they described positive and negative effects produced when using the prosthesis, highlighting that the use of the prosthesis allows them to talk about their condition. Finally, improvement proposals for the prosthesis are presented, defining that the prototype must be corrected and change the age of the target population. **Conclusions:** The study is the first to investigate a little explored topic, allowing to provide information regarding the subjective experience of adolescents who use a prosthesis that currently has great media importance. The study participants reported difficulties in using the hand prosthesis, either due to materiality and design aspects. The prosthesis did not meet the expectations of use and esthetic.

#### Keywords:

Hand partial amputation; prosthetics; 3D printing; rehabilitation; qualitative research

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## Introduction

Congenital upper limb deficiencies are alterations that occur during the gestational stage<sup>1</sup>, affecting completely or partially the development and growth of the upper extremities. Partial amputations are those in which there is a remaining segment of the limb, and complete amputations involve the absence of the upper limb<sup>2</sup>. Some amputations occur due to a syndrome and may be associated with other organ deficiencies<sup>3</sup>.

The existence of this impairment requires an adjustment on the part of the child and/or adolescent to life with amputation, where the family is a crucial factor<sup>4</sup>. Thus, factors such as depression, stress or other symptoms present in family members are often predictors of difficulties for children to adapt to the impairment, have good self-esteem and self-concept<sup>5,6</sup>, which directly affects their quality of life<sup>7-9</sup>. A study that assessed self-concept and psychological well-being showed that self-concept was not significantly different in groups of children with and without impairments<sup>10</sup>; however, children with mild abnormalities –such as partial hand amputations– had worse outcomes than those with severe abnormalities. It has also been reported that the psychosocial functioning of children with congenital impairments tends not to be different from that of children without impairments<sup>9</sup>.

Both data are fundamental when considering treatments for congenital upper limb deficiencies because although it is a minor physical alteration, it has been proven that this deficit significantly affects psychosocial functioning and well-being. These difficulties are even more relevant in adolescence since the determining aspects in the psychosocial sphere are body image, relationship with peers and the development of one's own identity<sup>11,12</sup>, therefore, the use of prosthesis is a must for patients with amputations<sup>13</sup>.

In the case of children and adolescents with congenital hand amputations, passive prostheses are preferably used as an esthetic element or active prostheses –mechanical or electric– that improve functionality<sup>14</sup>, however, this will depend on the level of amputation and functionality achieved without prostheses<sup>15</sup>. This last aspect is fundamental for adherence in this population, as low adherence to the use of prostheses has been reported in patients with limb sensitivity and/or grip function<sup>16,17</sup>. Adherence to the use of prostheses depends on factors such as type of amputation, age, sex, type of prosthesis, among others<sup>15,17,18</sup>.

## Clinical Case

This clinical case study was part of a mixed-type investigation aimed at evaluating the effect of the Cyborg Beast prosthetic hand on the functionality of the upper limbs. This prosthesis is a low cost mechanical orthopedic prosthesis developed with 3D printing technology<sup>19-21</sup>. This article will present the results obtained through qualitative methodology, which aimed to describe the experiences of five adolescents with congenital partial hand amputation and their caregivers, regarding the use of the 3D-printed orthopedic prosthetic hand Cyborg Beast, from a qualitative case study.

## Participants

The participants were five adolescents with congenital partial hand amputation from the Teletón Santiago Institute and their main caregivers (See table 1). Users with congenital hand amputation (left or right) aged between 12 to 17 years and residing in Santiago were included. All of them had similar physical characteristics in relation to the type of amputation. Five

**Table 1. Characteristics of participants and their caregivers**

Adolescent participants				Caregivers participants			
N	Age	Sex	Diagnosis	N	Age	Sex	Relationship to participant
P1	16	M	Left hand congenital deficiency. Agenesis fingers left hand	C1	76	W	Maternal grandmother
P2	14	W	Left hand congenital deficiency. Hypoplasia Thumb, longitudinal deficiency of fingers	C2	56	W	Mother
P3	16	M	Partial Hand Deficiency Left with short pinky and thumb remnants	C3	37	W	Mother
P4	14	W	Agenesis left hand	C4	52	W	Mother
P5	19	M	Síndrome de Poland	C5	52	W	Mother

M: man; W: woman; P: participant; C: caregiver.

patients were included because five prototypes of the orthopedic prosthesis were available, which were donated to Teletón. Each one was designed and customized for each user, according to the preference of colors and physical characteristics of their hand.

### Data production and analysis

Ten semi-structured interviews were conducted after finishing the period of prosthesis use (four months). The interviews were carried out at the Teletón Santiago Institute and were recorded. At each opportunity, the adolescent and his or her main caregiver were asked to attend the Institute, both were given the interview details and then were individually interviewed. For the data production, two interview guidelines were available, one for adolescents and another one for caregivers, which included questions on first impression, functions, social impact, choice of use, and meanings related to the use of the orthopedic prosthesis. For the analysis, a qualitative content analysis was carried out through open coding<sup>22</sup>, first, the interview audios were transcribed and then analyzed line by line, assigning concepts inductively.

### Ethical considerations

This work was approved by the Scientific Ethics Committee of the *Sociedad Pro Ayuda del Niño Lisiado*, (Project n° 43/2014). Participants signed assent and informed consent.

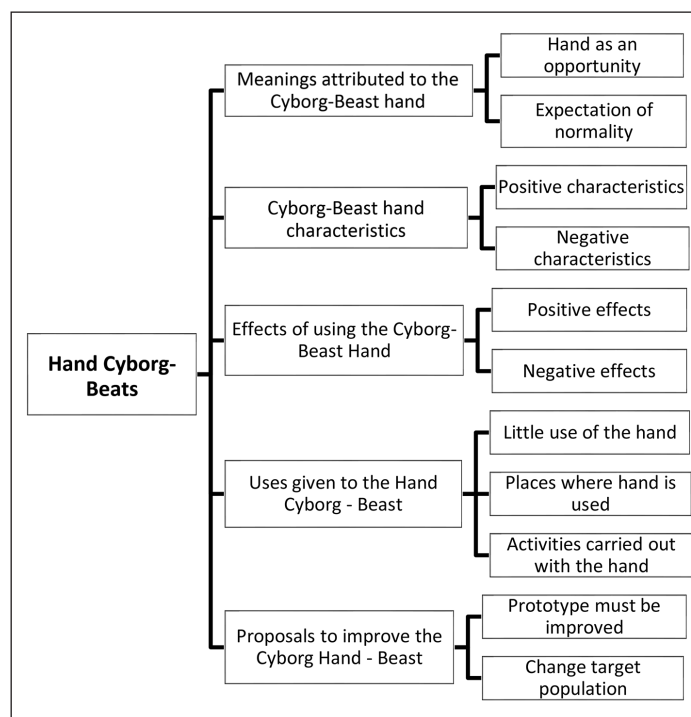
## Results

Five general categories were established from the analysis regarding the experience of using the Cyborg Beast orthopedic prosthesis (See figure 1).

### a. Meanings attributed to the Cyborg Beast hand

Adolescents and their caregivers conceive the hand as an opportunity because they feel privileged by participating in the study and in the evaluation of the orthopedic prosthesis, and also because they believe that the hand is an opportunity that will create better prototypes for children and young people who have an amputation. As reported by a caregiver *“it may not be what one expected, but I say maybe with this they’re gonna... in time they’re gonna do something else, so you can never refuse... to experience something that may at some point really be useful for you... that will make a contribution to your daily life”* (C2).

Adolescents mean the use of the hand with expectations of normality, indicating that they feel complete when wearing this prosthesis, which is evident as reported by one of the adolescents *“to see yourself with, with the five [fingers] already, that makes the difference*



**Figure 1.** Hierarchical organisation scheme of the categories and subcategories.

*(...) I for one, that I have this disease, as a boy always like, I thought, eh, how it would be and how I would look with the five fingers”* (P5).

### b. Characteristics of the Cyborg-Beast hand

Participants recognize that the orthopedic prosthesis has both positive and negative characteristics. As a positive feature, they recognize that it is easy to fix when damaged. In relation to the negative, adolescents and caregivers identify that the prosthesis is fragile, which is why users are afraid to wear it, because it can break easily, *“to use the hand I was told ... to squeeze to see the strength and I squeezed and this one, the moderator, the pressure moderator came out so that’s why I don’t use much it as it may come out and break”* (P3).

Both groups identify that the hand is not very functional, because it is less functional than their real hand and supports little weight, not fulfilling the expectations that they had when starting its use, *“the heaviest thing I grabbed was a glass of water (...) I think it was mine that was loosening up the whole little thing, so it was very, it was also much more difficult because of that”* (P5).

Finally, caregivers and adolescents identify that the prosthesis has esthetic problems, as it is very large, noticeable, rough, masculine, and robotic, which makes difficult its use in adolescents. As reported by a care-

giver, *"I believe it's strange. Because of everything, the bolts, eeeverything. I thought no, that it wasn't gonna be too noticeable, but... I don't know, it's kinda weird. I believe, it's not ugly, but it's not pretty either, I wouldn't use it in the street"* (C2). The caregivers add that these features would make the prosthesis more difficult to use in women.

### c. Effects of using the Cyborg-Beast hand

The use of the prosthesis, according to the participants, causes positive and negative effects. As positive effects, the adolescents indicate that the prosthesis has allowed them to talk about their disability with other people, *"you feel more comfortable, because when you talk to your friend and say: 'hey, I've got this hand!'", they say: "oh, that's cool, go to show it and you can touch the subject that before was not touched because it's embarrassing, or that someone could make fun of you"* (P3).

Regarding the negative effects, adolescents and caregivers report that the constant use of the prosthesis causes them injuries since the material used for making the prosthesis is made of a 'very hard' plastic. In addition, they add that its use causes discomfort since it is felt like an object foreign to the body, *"It's like I don't feel that it's part of me because (...) it's like something that I feel uncomfortable on top of my hand"* (P4).

Finally, there is some inconsistency in the discourse of the participants, since both groups identify that, although the prosthesis diminishes the difficulty to carry out certain activities, it causes difficulties to perform other actions. This can be observed in the report of one of the adolescents *"it limited movement, it limited it to me, I see the hand of [name a participant] and him, obviously he didn't have as much finger as I did, so it helps him, but for example it limited me a little more in doing things, in grabbing, to play the guitar, for example"* (P5).

### d. Cyborg Beast hand uses

Participants report that they little used the prostheses. As reasons for this low use, the adolescents indicated that they did not like using it, while their caregivers reported that the adolescents had difficulty adapting to it because it did not adapt to their needs. Both adolescents and caregivers added that the prosthesis was never used in schools and was only used at home. Both groups also added that those who accept their condition prefer not to use a prosthesis, *"I've been fifteen years with my normal hand, so give me a new hand is like... maybe a little shocking... I prefer my normal hand honestly (...) being sincere, quite honest, I prefer my normal hand (...) honestly... I feel..., like I'm satisfied with myself"* (P2). This discourse demonstrates that the participants in this study were used to using their hand with the functionality it already gave them, thus the

use of the orthopedic prosthesis was not a significant change for them. In relation to the uses given to the prosthesis, the adolescents indicated that the main activity they performed was grabbing objects, and the caregivers add that the adolescents used the hand to play or have fun with their relatives.

### e. Proposals to improve the Cyborg Beast hand

Finally, participants indicated proposals to improve the Cyborg Beast orthopedic prosthesis. First of all, they indicated that the prototype should be improved, increasing the colors variety, adding colors that are not very bright and 'similar to skin', *"I'd have more variety of color (...) because I was told that there was only pink (...) I'd also add like... skin, right, yes, more neutral colors, not so bright"* (P2). Both groups add that the adhesion of the protective silicones at the distal ends of the fingers of the orthopedic prosthesis should be improved and that it should be made more like a real hand.

Adolescents add that the prosthesis should have independent movement of the fingers, *"try to move the fingers because they're like, like normal hand movements (...) that's like a real hand, but, made of plastic"* (P1). All these improvements would make the prosthesis more like a real hand, causing an increase in its use.

Finally, the participants agree that the target population of the prosthesis should be changed, Cyborg Beast hand should be provided to the child population, since children could adapt more easily than adolescents *"I think that, at seven, eight (...), because like at that age it doesn't matter so much to them and... like when you're younger, they don't make fun so much"* (C2).

## Discussion

The results of the study show that the adolescents hardly used the orthopedic prosthetic hand since they had serious difficulties in getting used to it because they were adapted to their impairment, or because the prosthesis was perceived as a foreign object to their body, which was also too noticeable, so it did not comply with their expectation of 'normality'. Regarding manual functionality, the patients who participated in this study had already solved most of their activities with the remaining segment of the hand they had, therefore, they report that the biggest problem they see in the prosthesis is the esthetic, as they have tried not to continue drawing the attention of their environment with the prosthesis, since they feel they had already done it with the amputation before. What the participating adolescents repeated most was the need for the prosthesis to be as close as possible to a 'normal hand' which is related to studies that have evaluated self-concept in children with mild impairments<sup>10</sup>.

It is important to note that the participants reported difficulty in getting used to the prosthetic hand, which may be explained by increased concern about body appearance during adolescence, which generates great concern in adolescents with estrangement and rejection of their own body, insecurity regarding their attractiveness, and increased interest in sexuality<sup>23</sup>. This is particularly relevant in the case of adolescents with visible impairments, so incorporating a prosthesis during adolescence can be counterproductive<sup>4,9</sup> since, as indicated, adolescents claim that they have got used to 'not having a hand'.

This is reinforced by the participants who agree that it would be good to try this type of prosthesis in younger children, as they consider that acceptance by this age group could be better because they would not be used to their amputation and, due to their nature as children, they could see the prosthesis as a toy, being able to incorporate it more easily into their daily life.

The results of this study highlight the importance of incorporating the participants' expectations in the evaluation of prostheses or any technical assistance, often developed only from the point of view of design and engineering, being fundamental to also consider the stage of the life cycle that the patients are living. Finally, regarding the high expectations of the prosthesis use, it is believed that the high media diffusion as a result of the innovation the prosthesis implies, could generate higher expectations among the participants, therefore it is considered fundamental to continue developing studies of functionality and meanings, in order to generate evidence that can support decision making and the delivery of empirical information regarding these innovations.

## Conclusions

This study highlights the need to consider the vision and subjectivity of the users who will make use of

these orthopedic prostheses since adaptation to them will always be an individual experience, which will vary according to different areas, such as functionality achieved with the remaining segment of the hand, age, adaptation to the condition, and socio-cultural context; all elements described by the participants. The orthopedic prosthesis did not meet the expectations of use and esthetics.

## Ethical Responsibilities

**Human Beings and animals protection:** Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

**Data confidentiality:** The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

**Rights to privacy and informed consent:** The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

## Conflicts of Interest

Jorge Zúñiga is the designer of the prosthetic hand Cyborg Beast. The rest of the researchers declare that they have no conflict of interest.

## Financial Disclosure

Authors state that no economic support has been associated with the present study.

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