Global Social Acceptance of Prosthetic Devices

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***Abstract*— Social and societal pressures play an enormous role in the acceptance and use of prosthetic devices. Over the past 15 years, the United States has seen a radical shift in the mentality around prosthetic devices as amputees now choose function over form and encourage broader social acceptance of prostheses. This transition is not a global change, however, as seen in two different international studies: a preliminary study in Haiti that interviewed eight potential recipients about their interest in eNABLE-type partial hand devices; another which fit four patients in Jordan for such devices. In the Haiti study, in all but one case the devices were rejected on the basis of appearance (and resulting social and cultural implications), regardless of functional enhancements the devices might provide. To address these issues, and potentially increase social acceptance for amputees globally, new efforts and designs are being discussed.**

Keywords—prosthetic, additive manufacturing

I. Introduction

Significant demand exists for prosthetic devices in resource-limited circumstances; researchers, NGOs, and for-profit businesses have made numerous attempts to meet these needs [1]. Attempts to quantify this need varies widely, but conservative global estimates place numbers at more than 5 million people with major limb loss [2], with areas suffering catastrophic events such as war or natural disasters having significant increases in rates of amputation [3][2]. Although precise numbers are virtually impossible to obtain due to incomplete and patchwork national data collection systems[4], all indications are that this has been, and will remain, a significant global need.

A unique attempt to address the availability gap in underserved communities is underway by two groups affiliated with the eNABLE community – a global collective of designers, developers, makers, and hackers designing low-cost assistive or prosthetic devices for underserved segments of the amputee community. These devices, produced using low cost materials on commodity-3D printers, have the potential to reduce logistics chains and provide rapidly-deployable and customizable solutions via on-demand production.

The eNABLE community estimates more than 3,000 devices have been produced and fitted globally [4], almost exclusively to people who have a "partial hand" limb difference (i.e. an amputation or congenital malformation distal to the wrist, leaving some residual length and function of the hand). The vast majority of these devices have been fit in the United States. Although the greatest need is on the global stage, the evolution of the designs utilized in these studies evolved through input from a US, middle-to-upper middle class user constituency.

In order to have acceptance of a solution in any cultural setting, it must offer benefits that are in excess of cost. In the context of low-income countries and associated scenarios, cost is often measured with heavy bias towards financial elements [5]. Cost can however present in a number of other ways, including inconvenience and/or burden, social or community impact, and negative psycho-social ramifications [6]. Amputation itself presents both direct financial costs (due to loss of employment opportunity and/or work output, both perceived and actual) and non-financial costs in many societies. Any prosthetic device must provide a net positive effect either by providing improved functional capacity or addressing one or more of the many psycho-social or community impacts [7][8][9]. It is difficult, however, to determine the exact perception of benefit versus cost without conducting direct studies of the communities of impact.

Two pilot programs are exploring the viability for 3D printed upper limb assistive devices in the specific global contex of the developing worldt: the first with patients in Haiti, and the second with patients in the Middle East / North Africa (MENA) region. These areas were selected based on the following criteria: 1) presence of reliable partners, 2) existing security situation, and 3) demonstrable need of patients. These efforts focused on evaluating the practical and logistical feasibility of locally-printed prosthetics, as well as determining the perceived value of additional devices currently being developed by the eNABLE community. The pilots shared goals of identifying the current limitations of the devices given that they were not designed with these constituencies and their needs in mind and providing direct user feedback to the eNABLE design community, such that there is a representative voice for the target constituency.

II. Methods

A. Designs

The eNABLE community, as an inherently open, community- driven effort has produced a wide range of designs, reflecting, the aesthetic of its originator. This unstructured approach is at times less efficient but as the advantage of a more democratic approach to the design process [10]. At the time of these studies there were four basic hand designs and one partial finger design for evaluation by the communities in question (Table 1). Each design is accessed via the eNABLE repository [4]. These particular designs had been designed and evaluated for and by the eNABLE community with a primary focus of meeting the needs of pediatric patients suffering amniotic band syndrome, a congenital condition resulting in malformation of some or all digits of the hand. In that context devices of this type had received positive feedback and were thus considered valid candidates for this study [1]. Although known to have limitations based on both direct observation and concurrent studies by other groups [11] they comprised the best validated and most broadly produced devices available and were known to have at least some positive functional benefits in international settings [12].

TABLE 1 – ENABLE DESIGNS PRESENTED TO PATIENTS FOR REVIEW

Cyborg Beast (Jorge Zuniga, Creighton University, Omaha, NE)	
Raptor Hand (eNABLE community)	
FlexyHand (Gyrobot, LLC, Swindon, UK)	
Owen Finger (Ivan Owen, University of Washington Bothell, Bothell, WA)	
K1 Hand (Evan Keuster, 3DSystems, Rock Hill, SC)	

A. Studies

Two studies ran concurrently; however, as they were not designed or executed in a common manner, the research designs differed. Depending on the location, candidate patients suffered lib loss as defined in Table 2

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TABLE 2 – INDUSTRY STANDARD DEFINITIONS FOR LIMB LOSS [13]

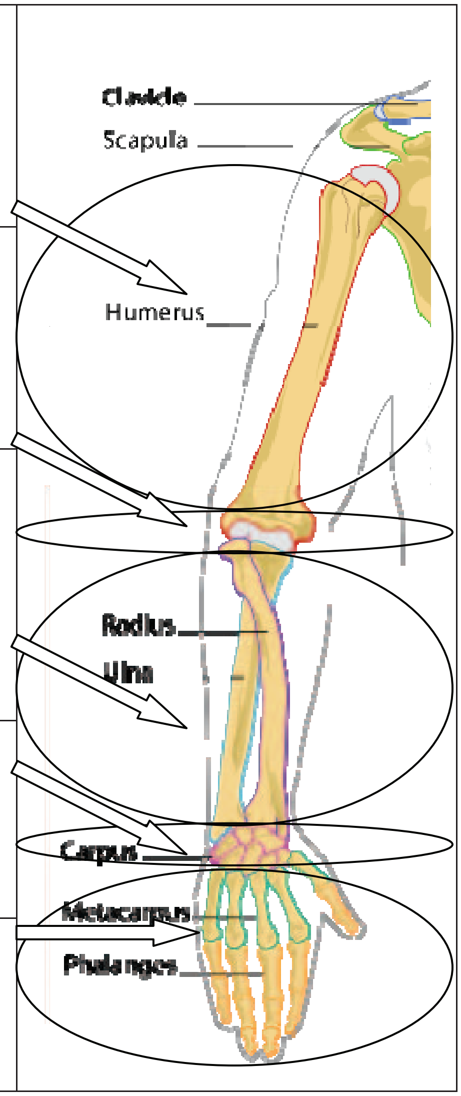
Transhumeral: Suffering limb loss between the shoulder and elbow joint, not inclusive of shoulder disarticulation or elbow disarticulation	
Elbow Disarticulation: Suffering limb loss via amputation within the elbow joint, leaving no portion of the radius or ulna but the complete humerus	
Transradial Amputation: Suffering limb loss distal to the elbow and proximal to the proximal carpal bones, not inclusive of wrist disarticulation or elbow disarticulation	
Wrist Disarticulation: Suffering limb loss between, directly proximal to or directly distal to the proximal or distal carpal bones	
Partial Hand: Suffering limb loss in a region distal to the wrist and inclusive of part or all of at least one digit	

Image: [14]

1) *Port au Prince, Haiti*

Enable International: Haiti (EIH), a group affiliated with the eNABLE Community, began working in August 2014 to determine the value and viability of 3D printed upper-limb prosthetic devices. The selection to work in Haiti by EIH was due to the recent earthquake in 2010, leading to an increase in the amount of amputations per citizen (although data is inconsistent on how many amputations were performed).

To understand value, the research focused on patient feedback of currently-available eNABLE devices. During the research, six potential recipients were interviewed in Jeremie, Haiti at Friends for Health in Haiti (FHH) and two potential recipients were interviewed in Titanyen, Haiti at Mission of Hope (MoH), and two recipients were interviewed in Port au Prince, Haiti at Hospital Bernard Mevs. These locations are significant representatives of end-user communities, as they provide feedback from rural, suburban , and urban populations. Interviews were conducted in English with the help of a Creole translator. The metrics of interest for the interviews were:

amputation causes and types, social and economic impact of the amputation, and initial reaction to the design of current 3D printed eNABLE devices.

TABLE 3: HAITI PATIENTS

ID	Age	Gender	Occupation	Prosthetic history	Type of amp.	Cause of amputation
H1	37	M	Mason	None	TR	Violent Attack (machete)
H2	43	M	Security guard	Traditional (2 mo)	TR	Car Accident
H3	27	F	Seamstress	Traditional (1 yr)	TR	Earthquake
H4	25	M	Fisherman	None	TH	Earthquake
H5	33	M	Mason	None	TH/ TR**	Electrocution
H6	22	M	Artist	None	TH	Infection
H7	30	M	Student	None	TH	Infection*
H8	29	M	None	None	TH	Infection*
H9	mid 20s	M	None	None	TR	Motorcycle Accident
H10	mid 20s	F	None	None	TH	Earthquake

Amputation Type: TR: Transradial, TH: Transhumeral, PH: Partial Hand

* Patient suffered injuries and sought treatment from a traditional healer

** Patient H5 suffered amputations on the right and left arm

2) Amman, Jordan

Refugee Open Ware, a nonprofit operating in Amman, Jordan, worked with patients recruited via the Jordanian Royal Medical Service (RMS). The RMS identified six candidates, which following the consideration of the inclusion criteria, were reduced to the four patients listed in Table 4. Inclusion criteria consisted of RMS staff approval, partial hand amputation, at least six months post-amputation, no existing wounds or injuries to the residual hand and distal half of forearm on affected side (i.e. the areas that would be in contact with the device), and appropriate devices were already available for the nature of the amputation.

TABLE 4: JORDAN PATIENTS

ID	Age	Gender	Occupation	Prosthetic history	Type of amp.	Cause of amputation
J1	Mid 20s	F	Home maker	None	PH	Household Accident
J2	Mid 20s	F	Hairdresser	None	PH	War Injury (Sudan)
J3	11	M	Student	None	PH	War Injury (Syria)
J4	6	M	Student	None	PH	War Injury (Syria)

Each patient was identified and critical measurements were taken. Patients were given the option of eNABLE approved designs available at the time shown in Table 2.

Devices were printed using an Ultimaker Original (Ultimaker BV, Geldermalsen, The Netherlands) using commodity ABS filament or FilaFlex flexible filament (Recreus, Valencia, Spain) depending on the selected design. Devices were printed and assembled per eNABLE's published guidance for each of the designs [4]. This work was performed at the Refugee Open Ware facility in Amman, Jordan; patients received the finished devices at a location convenient for them. Devices were provided at no cost to the patient; all costs of design and production were covered through Refugee Open Ware.

Once the devices were fitted, patients performed basic functional activities of grasping available objects and were asked their initial opinion of the device. When available, an informal follow-up verbal survey was conducted to assess of the use and perceived value of the device after two weeks

II. RESULTS

A majority (77%, CI 23.5) of eligible patients preferred the FlexyHand design. Patient J3, being only suitable for a single design, was not included in the statistical consideration.

A. Port au Prince, Haiti

The pilot of eNABLE devices in Haiti yielded an aversion to the current aesthetics of the eNABLE devices shown. As shown in Table 3, of the initial eight interviewees, seven showed a preference for the FlexyHand, and only one preferred the Raptor Reloaded, but specifically in black. A confounding factor to this research was that the shared devices were various colors including primary and secondary colors frequently chosen by child recipients in the US, potentially biasing results. However, there are many possible aesthetic reasons as to why the FlexyHand would be prefered to the Raptor Reloaded. The Raptor Reloaded has a less anatomically correct thumb placement, a less anthropomorphic palm, and more robotic joints when compared to the Flexyhand. Any conclusion relating to this however is conjecture as patients did not provide sufficiently specific feedback as to the reason for their aesthetic concerns.

It's important to understand the cultural drivers of Haitian patients; Vodou is a predominant belief system, particularly in more rural settings like Jeremie, Haiti. From the interviews, it was clear that Vodou drives a lack of acceptance for people with different abilities. Anecdotes conveyed a strong stigma towards amputees since a person's spiritual wholeness is tied to their physical wholeness. This likely contributes to increased value placed in the aesthetics of the FlexyHand.

Patients H9 and H10 received highly customized devices that were designed and produced in the field as no existing transradial or transhumeral solutions were available at the time. They both preferred to have a system fitted rather than walk away without one. The cases with initial feedback are described below. It is important to note the difficulty in follow-up assessments, as both individuals lived a substantial distance from the clinic in the case of Patient H9 or had no phone for remote follow-up communication in the case of Patient H10.

Patient H9: This subject identified the K1 hand in black as his preferred design. Per the guidance of the prosthetist, Patient H9 received a traditionally manufactured soft socket which was then sewn onto the K1 hand. There was a traditional figure-eight harness system installed which actuated the fingers of the K1

FIGURE 1: PATIENT H9 FITTING WITH FLEXYHAND TERMINAL DEVICE

hand. The patient did not like the requirement for the shoulder harness, but initially accepted the device after explanation of its necessity by the prosthetist. Although we have attempted to contact the individual, we have received no feedback after device reception.

Patient H10: Patient H10 was a transhumeral amputee with the desire of a cosmetic device capable of movement. With these specifications and limited resources, we designed a PVC-pipe arm with a 3D-printed ball-and-socket elbow joint and socket coupler. The socket was a traditionally manufactured soft shell along with a rigid polypropylene exoshell. The socket coupled with a traditional figure-eight harness on the proximal end and with a 3D-printed coupler on the distal end. A line from the shoulder harness anchored in the form-arm PVC pipe, and actuated when the residual limb was lifted away from the torso by the subject. The terminal device was a static Flexyhand in black as per Patient H10's request. There was a coupler added to the Flexyhand to interface with the PVC forearm. Patient H10 was accepting of the aesthetics of the device upon reception, but infrequently used it when asked during a follow-up six months after the device reception. The patient has received a new device for which we are awaiting more regular feedback.

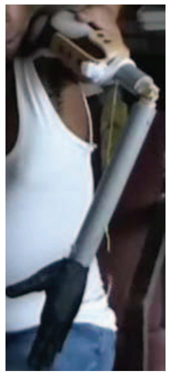


FIGURE 2: PATIENT H10, TRANSHUMERAL ENDOSKELETON FITTED WITH FLEXYHAND TERMINAL DEVICE

B. Amman, Jordan

Device selection for the Jordan patient set was diverse; working from photos to communicate preference, patients J1 and J4 selected FlexyHands, patient J2 selected a Cyborg Beast, and, patient J3 selected the Owen Finger (note: this was the only device appropriate for the amputation).

Patient J1: Patient J1's FlexyHand was produced In dark gray per the user's request to create an approximate match to skin tone and reduce visual appearance of size. Within 3-4 minutes of receipt, the patient was able to use the device to assist in cooking tasks (e.g. holding a zucchini while cutting with the contralateral hand) and fix her daughter's hair. Aesthetic perception of the device, however, was low; particular concern was expressed about the apparent size, artificial color, and robotic nature of the hand. At a two week followup, the patient had generally ceased use despite the desire to use the device in in specific circumstances, citing low utility and high aesthetic burden.

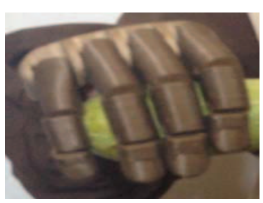


FIGURE 3: PATIENT J1 USING FLEXYHAND FOR HOME TASKS

Patient J2: This subject identified the Cyborg Beast as her preferred design. Per the patient's request, designers customized the hand and wrist with Arabic script lettering. Initial perception of the device (upon seeing photos) was positive and suggested that, with the appropriate customization, the device would be well accepted by the user. Upon receipt, the patient expressed that the device met her expectations, yet at two-week follow-up indicated that she had within one day rejected the device due to overall size and and its non-anthropomorphic appearance.

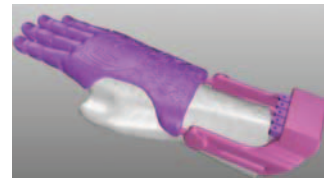


FIGURE 4: CUSTOMIZED CYBORG BEAST FOR PATIENT J2

Patient J3: Due to the nature of Patient J3's amputation and the length and function of the residual fingers, the Owen Replacement finger the only viable option. The design, however, was practically unworkable as the residual finger was too short to provide suitable retention. The subject did not express concerns about the design aesthetics however the device's function was so poor that the quality of that judgement may not be reliable.

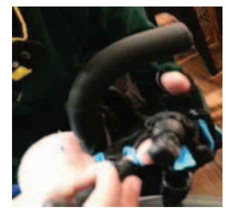


FIGURE 5: PATIENT J3 WITH OWEN FINGER SYSTEM

Patient J4: In an attempt to increase acceptance and use, the FlexyHand produced for Patient J4 was highly customized, including electronics to display cartoon characters from the boy's favorite TV show ("Ben 10"). The device was initially very positively received by the recipient. Upon follow-up, however, utilization had been reduced to only occasional use in-home, citing pressure from the family around the perception that the design aesthetics were "embarrassing". Subsequent follow-ups showed little to no use.

FIGURE 6: CUSTOMIZED FLEXYHAND FOR PATIENT J4

III. DISCUSSION

Two key observations were made from evaluating, producing, fitting, and following-up on the devices: the currently-available portfolio of 3D-printed limbs must be expanded to accommodate the complex amputations in the developing world; and design cosmetic coverings (generally referred to as a 'cosmesis' which provides an appropriate representation of the human body's weight and aesthetics) is paramount.

A. Aesthetic Considerations

Currently-available designs for 3D printed upper limb prosthetic devices do not meet the aesthetic expectations of the communities being served. Even devices initially seen as desirable (e.g. the Cyborg Beast and FlexyHand by patients J2 and J4, respectively) or providing additional dexterity and functionality (e.g. FlexyHand for patient J1) were rejected. This was essentially because the devices drew attention to the amputee's limb difference rather than serving to de-emphasize them which was the overarching desire of recipients.

The regions discussed – the Middle East, Africa and Caribbean – are highly aesthetically sensitive. In fact, arguably, the United States and Europe are the exceptions in their increased social acceptance of non-anthropomorphic prostheses, and even this is a relatively new phenomenon and body image issues remain for this population as well [11][15][16].

Addressing this desire for cosmesis using on-demand additive manufacturing is challenging because of issues related to materials and the inherent design process used in currently available devices. Parts printed with FDM (fused deposition modeling) have low material strength, and thereby require fairly bulky designs to prevent mechanical failure. Some early designs compensated for the weaker material strength by placing the finger joints on the distal end of the frame, but resulting in a hand that is unnaturally wide and bulky. Finally, the basic appearance of hard plastic, regardless of the color, differs significantly in luster, finish, and organic shape and form from the human hand.

Cultural stigmas outside the U.S. dictates that the prosthesis appearance be as anthropomorphic or 'natural' as possible (understandably, there is a risk of moving towards the uncanny valley and creating a device that is too lifelike, which will be explored in future work). This is consistent with regional experience and expectations in commercial prosthetics. Discussions with regional prosthetic providers indicate that prosthetic clinics in the Middle East do not use stock hooks, the most broadly-used body-powered device in the West, because they are deemed unacceptable by local patients [17].

B. Design Portfolio

In the Jordan study, two patients were immediately rejected and one more subsequently could not be helped due to the limited portfolio of designs. The eNABLE community designs almost exclusively target partial hand amputations with no residual digits; unfortunately, this represents a small proportion of the amputee population. Although actual numbers of patients with this type of amputation in the region could not be quantified, discussions with UNICEF (Damascus), Red Crescent Society of Qatar (operating in Lebanon), the Jordanian RMS, and NSPPL (a prosthetics nonprofit operating in Turkey and servicing Syrian refugees) estimate that it would be difficult to identify a sufficiently large patient population to warrant investment into the current design offerings.

Even within this narrow space, existing devices poorly meet the needs of the various partial hand amputations, including those with residual digits. Current designs require that the amputation be: complete, no more proximal than the middle of the palm, and no more distal than the metacarpo-phalangeal joints (knuckles); a more proximal amputation yields insufficient leverage to actuate the mechanism and a more distal (i.e. leaving residual fingers) amputation interferes with the prosthetic.

In order to appropriately serve these communities additional designs will need to be developed including: transradial / transhumeral devices that accommodate or adapt to existing ICRC socket designs; easily produced, purely cosmetic devices that enhance social acceptance; and ultimately, full prostheses, including customized sockets, produced using locally available staff and taking into consideration their relative training level.

IV. Conclusion

Advocates for low-cost devices in resource-constrained communities assert that "something is better than nothing", that providing some improvement in the user's functionality is sufficient motivation to warrant the required investment. However, as evidenced by these pilot studies, the social and cultural desires of the serviced communities must be met in order to drive any device adoption. Otherwise, the devices will be quickly rejected, regardless of the perceived or apparent value of an assistive device, and patients are likely to leave with a negative perception of the capacity of prosthetic devices to meet their needs. As with all projects translating successes from the US to other cultures, cultural sensitivity is paramount to drive adoption.

A second set of observations revolved around the need to expand the design portfolio of available devices and solutions to accommodate a broader range of patients, particularly expanding into meeting the needs of the much larger transradial and transhumeral amputation community. As evidenced by the examples of patients receiving devices that were rejected for aesthetic reasons, these designs should follow a fundamentally different path of addressing the visual and cultural expectations first, and designs reflecting this are already in-process within the eNABLE community.

Global design efforts - including that of the eNABLE community - continue to drive forward innovation in 3D printed prosthetic devices with practical and psychosocial impacts. Their early focus to meet the needs of Westerners however has limited the designers' ability to address the needs of the global community. With appropriate user-centered design, initiated by the projects described here, the design community can produce devices that are more closely aligned with the global needs and therefore have a larger impact on the global amputee community.

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