

The Global Ecosystem of 3D Printed Assistive Devices for Upper Extremities



Figure 1. We interviewed people from different countries who participate with their community in the ecosystem of 3D printed assistive devices for upper extremities. Figure 1 showcases some of our participants from the U.S., Mexico, and India.

ABSTRACT

A new ecosystem has been expanding globally where communities from different countries are coming together to fabricate 3D printed assistive technology (i.e., A.T.) for upper extremities, such as arms, hands, and fingers. However, despite its expansion, we currently lack information about how communities in the ecosystem outside the U.S. and Canada operate, or what challenges they experience. The lack of information about how other parts of the world organize means that what we take for granted in one context is not necessarily true in another. In order to make improvements and have a broader adoption of 3D printed assistive devices at scale, it is critical to understand how people from different socio-political regions are organizing to fabricate and deliver A.T. Through a two-year process, we connected and interviewed 31 individuals from seven countries working within different communities in the ecosystem. Our research provides the first broad glimpse of how individuals from different countries operate within the ecosystem. We finish by discussing design opportunities to improve global fabrication of 3D printed A.T.

1. Introduction

In recent years, communities focused on designing, fabricating, and using 3D printed assistive technology (also known as A.T.) for upper extremities such as arms, hands, and fingers have emerged globally [1]. These communities generally involve three main actors: (1) *the makers* of the 3D printed A.T. for upper extremities (also referred to in medical terms as “prosthetic devices” or colloquially as “devices”); (2) the *end-users* who receive and use the 3D printed A.T. (usually called “recipients”); and (3) the *healthcare practitioners* who provide therapy or medical assistance to recipients. Following ecology terminology [2], we view the collection of all of these communities as an ecosystem. Previous research has mostly investigated the experiences of individual actors within the ecosystem, but not how different actors operate together as a community. For instance, Lakshmi et al. [3], examined the activities of individual makers and resources they used to fabricate medical devices. The work provided an in-depth analysis of the perspectives of makers on digital fabrication for medical practice. However, the work did not connect the experiences of makers with that of recipients or of other actors in their community (e.g., healthcare practitioners). Similarly, previous studies have analyzed the experiences of recipients [4,5]. The research uncovered how the A.T. helped recipients develop a sense of identity and normalcy. However, there was again a limited investigation into how recipients interacted with other actors.

Studying the perspectives of only one particular actor at a time has limited our ability to gain a broader view of how these communities operate (*i.e.*, how the different actors in a community are connecting and collaborating with each other). Additionally, most of these prior studies have

focused only on the U.S. or Canada [6,7,1,8]. This has led us to have blinders on as to how exactly the ecosystem is playing out in different parts of the world. We currently lack an understanding of how the *modus operandi* might change between regions.

One main barrier for understanding how these global communities are playing out in the wild, is that the ecosystem in general has not released information about their participants, making them difficult to interview. To our knowledge, research is non-existent concerning how communities outside the U.S. and Canada operate. However, understanding how the global ecosystem functions is critical to identify challenges and pathways to a broader acceptance of the devices.

To address this gap, we worked closely for over two years with globally dispersed communities from the ecosystem of 3D printed A.T. for upper extremities. This empowered us to access 31 individuals distributed across seven countries who had different roles within their communities. These individuals were makers, healthcare practitioners, and recipients located in Brazil, Chile, Costa Rica, France, India, Mexico and the U.S. Through our study, we start to provide a glimpse of the different ways communities in the ecosystem from different socio-economical regions organize to fabricate 3D printed assistive devices and deliver them to real world recipients. We conclude by discussing design implications of our findings.

2. Related Work

Table 1.

Research Method	Reference	Healthcare	Maker	Recipient	Country
Report & Interview	Hofmann [1]	Healthcare	Maker		U.S.
Semi-Structured Interviews	Lakshmi [3]	Healthcare			U.S./Canada
Two-site case study	Hofmann [19]	Healthcare			U.S.
Interviews	Parry-Hill [7]	Healthcare	Maker		U.S.
Interviews	Okerlund [6]		Maker		U.S.
Case Study	Hawthorn [4]		Maker	Recipient	U.S.
Case Study & Interviews	Hurst [13]		Maker	Recipient	U.S.
Interviews	Bennett [5]			Recipient	U.S.

Table 1. Summary of prior research, detailing research method and area of focus. Most have not foregrounded the global nature of this activity

Assistive Technology (A.T.) is defined as any piece of equipment that is used to maintain or improve the functional capabilities of individuals with disabilities [26]. Unfortunately, most A.T. is expensive and has difficulty adapting to recipients' changing needs [8,27]. Therefore, most A.T. is abandoned [9,28]. To overcome this, researchers and practitioners have turned to 3D printed A.T. as it is highly customizable, economical, and allows for rapid prototyping [10]. As a result of the promise of 3D printing, an ecosystem where communities of people coordinate to fabricate and use 3D printed A.T. has been on the rise globally [24,25,29]. In the following, we cover the research that has been done around this emerging ecosystem (especially, regarding the main stakeholders) and highlight the knowledge gaps that exist (see Table 1).

2.1 Healthcare Practitioners and 3D Printed Assistive Devices

Past research has investigated the perspectives of healthcare practitioners with regard to the design and prototyping of 3D printed A.T. [3,15], as well as medical making of devices in general [30,31,32]. Notice that similar to prior work [3], we consider healthcare practitioners to be individuals who practice medicine or who provide any type of health-related services to recipients. Given that one of the main concerns of healthcare practitioners is ensuring patient safety [33,31,19],

and 3D printing technology has not been thoroughly tested, many healthcare professionals, especially from the U.S. and France, have been more reluctant to find merit in 3D printed A.T. [1,9,7]. Prior work has primarily found that most healthcare professionals are usually only involved in critiquing work-in-progress [34], rather than being heavily involved in the fabrication or adoption of 3D printed A.T. [7]. However, it is noteworthy to mention that most prior work has focused only on the U.S. and Canada [3]. Consequently, we are figuratively operating with blinders on. It is unclear whether all healthcare practitioners are operating from the “sidelines”, or whether this is a finding that holds true for only certain regions. It might be that in some parts of the world healthcare practitioners are more receptive and are actively involved in the fabrication of 3D printed A.T. Our research aims to broaden this perspective, and provide a glimpse of how these different actors operate.

2.2 Makers and 3D Printed Assistive Devices

Since 2013 we have seen the global rise of maker communities that focus on designing, fabricating, and distributing 3D-printed assistive hands [2,24,14]. The maker movement provides an opportunity to disseminate low-cost solutions for health care at scale, and to improve the design of health innovations through open-source collaborations [15,35]. For example, the e-NABLE community (<http://enablingthefuture.org/>), one of the largest communities where people coordinate to fabricate, distribute, and use 3D printed A.T., started when a boy developed a 3D printed assistive hand prototype and published online the files of his design in an open-source format. By enabling individuals to download and print the A.T., it allowed for iteration and improvement of the designs within the community, which currently has over 7,000 members with over 2,000 devices created and gifted to individuals in over 45 countries. The majority of these maker communities emerged through NGOs, such as e-NABLE and more recently through emerging collaborations with industry [16,17]. These maker communities have the general goal of making 3D printed A.T. for people with upper limb differences more accessible [7]. They focus on populations for whom traditional A.T. is too expensive [18,15]. The U.S. has several maker communities (e.g., the Open Hand Project, Open Bionics, e-NABLE, Limbitless) committed to a similar mission [14]. Several chapters and spin-offs of these communities have also emerged worldwide (see e.g., the map of e-NABLE chapters across countries: <http://enablingthefuture.org/e-nable-community-chapters/>).

However, most related work has focused again on studying these maker communities only within a single country, usually the United States [7,11,12]. These prior investigations have uncovered that U.S. makers typically lack close connections to healthcare workers, a structural situation which has raised concerns about health and safety implications of the ideals driving the work of Do-It-Yourself communities [36,37,38,39]. It is simple, not having healthcare practitioners work with makers threatens the long-term existence of 3D printed A.T. Without the support of healthcare workers, it is unlikely that the devices could address the medical needs of recipients. In this work, we are interested in exploring how maker communities in other parts of the world operate. Are there maker communities who have been able to connect with healthcare workers? Such cooperation might provide more hope to the long-term existence of the ecosystem. We expect that we might find evidence of other types of relationships between makers and healthcare practitioners than those observed in the U.S. because research about a single country typically presents a limited perspective. The findings from prior work likely were limited by regulatory and cultural expectations. We therefore expect that by studying other countries we might uncover a wider variety of ways in which healthcare practitioners and makers collaborate with each other.

2.3 Recipients of 3D Printed Assistive Technology

Looking beyond the narrow focus on a single country that was described above, existing work has another important limitation: The voices of recipients (i.e., the people with disabilities who receive the devices) are

rarely represented in the literature [40,23]. One of the reasons for the limited research around recipients is that it is difficult to recruit recipients. Public information about them is usually not available. We have not been able to identify any reports or documentation by maker communities about their recipients (though recipients are often mentioned in the news [5,41,42]). As a result, most existing studies are smaller scale. Hawthorn and Ashbrook were one of the first to start to document the experiences of individuals who received 3D printed assistive hands [4]. However, their work focused on a single U.S. e-NABLE recipient. Bennett et al. [5] interviewed five adult U.S. recipients to begin to understand some of the usages for their 3D printed A.T. hands. Other related research [13,5,11] reports on the experiences of makers of A.T., who were also recipients. The studies found that recipients had a keen interest in being involved in the process of creating and defining their own A.T. However, these studies were again limited to a single region (the U.S. and Canada). This consequently limited the range of experiences to only represent people from that particular cultural context. Additionally, as Hawthorn et al. [4] notes, we lack an understanding of the type of follow-up that recipients are receiving (note that similar to prior work, we define follow-up as contact with the recipient within the ecosystem after the device was delivered.) With this study we hope to start to shed light onto the different ways in which recipients participate within the ecosystem.

3. Methods

Our goal is to shed light on a variety of structural alternatives within the ecosystem of 3D printed A.T. for upper extremities. We were interested in understanding the similarities and differences that existed across different international contexts. For this purpose, we conducted a qualitative study consisting of semi-structured interviews. Between August 2018 and August 2019, we interviewed 31 people who either: received and used 3D printed assistive technology (*recipients*); made 3D printed A.T. (*makers*); provided any type of medical assistance or therapy assistance for the operation of the devices (*healthcare practitioners*).

3.1 Participants

In order to access and recruit these actors, we first formed a collaboration for over two years with two groups: e-NABLE and related Latin American NGOs. The first collaboration involved one of our researchers who volunteered with the e-NABLE community. She eventually joined the strategic planning committee and initiated a sub group to study device use (with open membership to anyone interested). Several of the other co-authors also joined that group. This collaboration with the e-NABLE community provided us access to a list of recipients, as well as lists of makers and health professionals active in the fabrication of 3D printed assistive devices across different countries (as e-NABLE has chapters and spinoffs in different parts of the world). Our second collaboration involved researchers from our team who volunteered with NGOs in Latin America. Similarly, this gave us access to recipients, makers, and healthcare practitioners from the region. Our connections with these organizations were likely facilitated because our researchers are both native Spanish speakers from Mexico and native English speakers from the U.S. Additionally, we searched for participants using social media and news reports. Our direct engagement with people involved in the ecosystem helped us to identify where individuals were gathering online to discuss about 3D printed A.T. for upper extremities. We posted in these online spaces (which involved the platforms of Twitter, Facebook, Google +, Reddit) to invite further participants to our study. We also used snowball sampling to recruit more individuals.

3.2 Data Collection and Analysis

Our interviews focused on eliciting information from our participants about how they participated in the ecosystem of 3D printed A.T., how they organized and worked with other actors (pain points and high points), as well as their thoughts on having the maker culture (a technology driven, Do-It-Yourself craftsman subculture) be involved in assistive technologies. Given that our goal was to

dig deep into how different actors interacted and worked with each other in the ecosystem, we added specific questions for each type of actor (recipients, makers, and healthcare professionals) that built on existing survey and interview studies for those roles. All of our questions were vetted by people knowledgeable about the e-NABLE community and 3D printed A.T., and built off existing related research [7,1,3].

We did the interviews in either English or Spanish (in which case they were translated to English for the group analysis.) For our data analysis, we looked for general patterns on how people operated within the ecosystem and experiences they had. We aggregated all the interview responses from participants, as well as all our notes and memos from the study, to start to identify key concepts and ideas. We used open coding to extract initial concepts from the interviews [20]. We aimed for these initial concepts to take into account some of the themes that related work had derived [7,1,3]. Next, we discussed these initial concepts in their entirety to underscore the importance of them for the ecosystem. With this initial list of codes established, the first and second authors then independently coded the data bottom-up and created a set of 18 axial codes which were applied top-down to the interview transcripts. From the 18 axial codes we collectively derived a list of themes representing the different experiences and insights that participants reported. Our analysis showed strong inter-coder agreement (Cohen's Kappa coefficient(k) = 0.765). Disagreements were discussed during the writing and synthesis process. We use our thematic analysis to structure the responses of our participants, and highlight the differences and similarities of their operation. The themes we discovered were:

- **Support for Quality Work:** This theme includes the resources that our maker and healthcare participants adopted to ensure quality in: (a) the 3D printed A.T. for upper extremities that they produced; and (b) the therapies or medical attention given to recipients. Some of the resources that maker participants used to ensure quality included the space where their teams operated or teaming up with healthcare practitioners.
- **Recipient Feedback:** This theme examines how the feedback from recipients is dealt with and incorporated to improve the ecosystem.
- **Global Differences:** This theme is about the global differences that our participants experienced in the fabrication of 3D printed A.T. for upper extremities, and how the process was adapted to the specific country of fabrication and distribution.

4. Results

In total, we interviewed 31 participants with due consent from the IRB boards of our universities: 16 recipients; 9 makers; and 6 healthcare practitioners. In the rest of the paper, we refer to our participants who are recipients with the identification of "-R", makers with "-M", and health practitioners with "-H". In general, our maker (M) and healthcare (H) participants worked either within companies and/or NGOs dedicated to the production of 3D printed A.T. However, some of our participants had more complex appointments where they additionally worked in the government or universities. Table 2 presents the details of our participants. For instance, H5 and H6 worked in state run hospitals, volunteered in their local e-NABLE chapter, and were also university professors. M5 worked for the local government and was also a volunteer at e-NABLE. Similarly, M2 worked in a state-run hospital, volunteered at e-NABLE and took part in government affairs to move legislation around 3D printed A.T. Some participants mixed working in hospitals and NGOs, such was the case of H1 and H2.

However, despite our participants' diverse backgrounds, we identified that all our interviewees reported, in general, a similar process of operation:

1. A recipient provides information about their condition (e.g., type of limb loss), her measurements, and her needs.
2. Given the information, the most suitable device is designed and built for the recipient.
3. The finished device is then delivered to the recipient.

While all our participants followed these three main steps, we also importantly identified key operational differences in how our participants served the needs of recipients: The type of support that our participants utilized in their operation varied significantly (represented in themes “Support for Quality Work” and “Global Differences”). Similarly, the type of follow-up they provided varied (represented in themes “Recipient Feedback” and “Global Differences”).

Table 2.

ID	Role	Location	Details on the Participants	Gender
R1	Recipient	U.S.	Hand from NGO	Male
R2	Recipient	U.S.	Hand from NGO	Female
R3	Recipient	U.S.	Hand from NGO	Non-binary
R4	Recipient	Mexico	Hand from NGO	Female
R5	Recipient	Mexico	Hand from Hospital	Female
R6	Recipient	Mexico	Hand from Hospital	Male
R7	Recipient	Mexico	Hand from Hospital	Male
R8	Recipient	Mexico	Hand from NGO	Female
R9	Recipient	Mexico	Hand from NGO	Female
R10	Recipient	Chile	Hand from Hospital	Female
R11	Recipient	U.S.	Hand from Company	Male
R12	Recipient	U.S.	Hand from NGO	Female
R13	Recipient	U.S.	Hand from Company	Male
R14	Recipient	U.S.	Hand from Company	Male
R15	Recipient	U.S.	Hand from Company	Male
R16	Recipient	U.S.	Hand from Company	Male
M1	Maker	U.S.	Works at Company	Male
M2	Maker	Brazil	Works at NGO, Government and Hospitals	Male
M3	Maker	U.S.	Works at NGO	Male
M4	Maker	France	Works at NGO	Male
M5	Maker	India	Works at NGO and Government	Male
M6	Maker	U.S.	Works at Company	Female
M7	Maker	U.S.	Works at NGO	Female
M8	Maker	U.S.	Works at NGO	Male
M9	Maker	U.S.	Works at NGO	Female
H1	Healthcare	Mexico	Works at Hospital and NGO	Male
H2	Healthcare	India	Works at Hospital and NGO	Female
H3	Healthcare	U.S.	Retired Occupational Therapist volunteering at NGO	Female
H4	Healthcare	U.S.	Works at Hospital	Female
H5	Healthcare	Costa Rica	Government Physician; works at NGO and University	Female
H6	Healthcare	Mexico	Government Physician; works also at NGO and University.	Male

Table 2. Overview of the characteristics of our participants.

4.1 Operational Differences: Type of Support

The largest differences that we identified in the ecosystem was whether makers connected with healthcare practitioners to receive support in the fabrication of 3D printed A.T. for upper extremities. Our U.S. participants rarely mentioned connecting with or working with healthcare practitioners, which is not surprising given what has been found in prior work in the U.S. [1,3]. However, all of our non-U.S. participants reported that they worked closely with healthcare practitioners to support their operation. For instance, M2 (a maker from Brazil) discussed how makers in his country received constant support from healthcare practitioners:

“...the first step is that we ask [recipients] two things. First: do you have a doctor? If he has a doctor, we schedule a meeting with this doctor [...] and we ask this doctor, who knows about the case and the patient, to evaluate the devices and based on that to say what is the device we need to create for the kid. So, we [the makers] do not choose, also the recipient does not choose. The doctor is the one who will tell us what needs to be printed [...] If the kid doesn't have a doctor [...] we try to find a doctor near the city [...] and we approach this doctor [...] and ask him to help this person with his evaluation. So, the doctor is the first step...” M2, Brazil.

Similarly, our participants from India also discussed how they used the support of local hospitals to help makers define the type of A.T. for upper extremities to fabricate; as well as to train recipients on how to use their devices:

“...We have a visiting doctor [...] if we have a patient coming, he does the training [training to help the recipient learn how to utilize and adopt the device] [...] and we have a prosthetic technician. So, he [the prosthetic technician] assesses the hands and he modifies the hands. He tells us what tools to use and when we have a challenging beneficiary [recipient], he gives us ideas on how we can modify the design...” H2, India.

Our participant from France, M4, also discussed how he and his team leveraged the help of healthcare practitioners to be able to design and deliver novel types of devices:

“...We're working [...] to create a new device [...] we needed to create a shoulder harness, something that we didn't know how to do. So, we are working with this hospital and the prosthetics company from the hospital and the occupational therapists that are working at the hospital [...] So if we manage to work together it would be a new device for an entire arm...” M4, France.

For our non-U.S. participants, teaming up with healthcare practitioners to support their operation appeared to be key to safeguard quality and longer-term adoption of the devices they fabricated. M2 (maker from Brazil), for instance, discussed how NOT involving healthcare practitioners could lead to cases where the devices turned into “toys” and were hence not used long term:

“...if we don't have a team [team of doctors, prosthetic technicians, and therapists] helping the recipients to make it right to their size, to make them really know that that is not a toy, it is a medical device, in one or two months, the kid stops using it...” M2, Brazil.

In contrast, our U.S. participants rarely described collaborating with healthcare practitioners. This is consistent with reports on the viewpoints of healthcare workers on maker produced A.T. [1]. Our U.S. participants reported that healthcare professionals in their country were skeptical of 3D printed A.T. for upper extremities:

“...professionals [healthcare professionals] are more skeptical and won't work with us...” M3, USA.

Our U.S. participant, M9, elaborated on why she rarely relied on healthcare practitioners. She believed that healthcare practitioners in the U.S. focused more on their business model than on providing “social support” due to governmental restrictions and financial reimbursements:

“One of the reasons we [his local U.S. e-NABLE team] don't really work with them [hospitals] is that they have a lot of strict regulations [...] You have the FDA, the insurance companies [...] There are probably a lot of corporate interests involved [...] They [healthcare practitioners] don't really care about collaborations or giving support. They follow their business model....” M9, USA.

While our participants are not experts on all of the structural forces in play, these widely varying reports demonstrate the importance of studying 3D printing and making in multiple contexts. What is taken for granted in one context is not necessarily true in another. While participants may theorize about *why* communities in the U.S. do not include health professionals, there is little evidence that they have overcome the forces arrayed against such collaborations; and even less evidence about the positive or negative impact on recipients of making without such collaborations. In contrast, participants in other regions similarly take for granted the involvement of healthcare professionals in their work. By uncovering how these individuals from different geographic backgrounds engage with health professionals and their communities, we gain a greater understanding of all maker communities.

4.2 Operational Differences: Type of Follow-up

Another important difference we observed between the operations of our participants was in the type of follow-up provided to recipients, i.e., how the different actors in the ecosystem engaged or contacted the recipient after the device has been delivered. All of our non-U.S. participants had detailed procedures and guidelines for follow-up. Meanwhile, only a few of our U.S. participants described doing follow-up and it occurred less often. The follow-up process of our non-U.S. participants generally involved: (1) meeting with recipients to understand their experiences with the device; and (2) iterating on the devices to better cover the needs of recipients, as well as provide therapies to make the devices more comfortable. For instance, a recipient from Mexico described these two main steps in the follow-up she received:

“Once the device is ready, they call us back. We pick it [the device] up and setup a schedule for therapies so we can learn how to use the device. The device is sometimes modified to better fit us...” R8, Mexico.

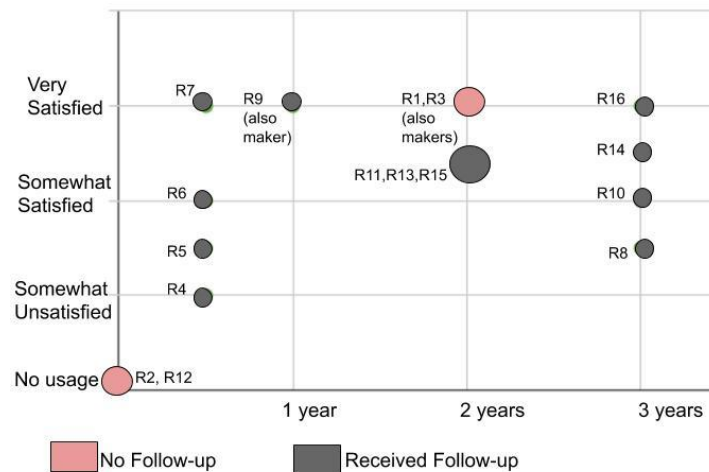


Figure 2. Overview of the follow-up our recipient participants received and how it connected to device usage and device satisfaction. Overall recipients had varied experiences with their devices.

Similarly, the following quote from a maker in India helps to showcase the type of things our participants asked their recipients in the follow-up, and why they asked those questions:

“What we [makers and healthcare practitioners] like to know [in the follow-up] is how much they are using the hand [i.e., the device] [...] we would like them to increase the usage of the hand as time goes by [...] We also ask the beneficiaries [recipients] for ideas just like how we asked Pradeep [name changed; he was one of their recipients] what works better.” M5, India.

Our participants used the feedback they received from recipients to help them improve the devices. For example, M5 also discussed how he used the feedback from recipients to create better 3D printed A.T. hands, in this case, hands that resembled a spoon form:

“...We also ask the beneficiaries [recipients] for ideas just like how we asked Pradeep [recipient] what works better. That's why he has a modified spoon [his 3D printed hand had a spoon at the end where fingers would normally be]. Because he said it was very discomforting to eat with it the way it was [the way the 3D printed hand was originally]. [...] So feedback from the beneficiaries [recipients] is very important as well.” M5, India.

Similarly, a recipient from Mexico discussed how through follow-up she was able to iterate her device with her doctor to better tailor it to her needs:

“...These sessions [follow-up sessions] have helped me to start to craft with my doctor my ideal device [...] My ideal device is one that will make me feel the same way I felt before losing my hand. One that will help me to go unnoticed. My ideal device is one that will help me to re-establish the image I had about myself before the accident and with the same functionalities that I had before...” R5, México.

It was also interesting to see the concerns that our participants expressed with the follow-up. One that was prominent was that their recipients might not be able to afford to travel to do the follow-up. To overcome this problem, our interviewees mentioned that they created mechanisms to cover travel costs and also motivate recipients to attend the follow-up:

“...some of them [recipients] didn't come initially [to the follow-up] because they didn't have the money. They're really, really poor so what we started to do is that [...] we pay their transport and give them a meal [...] So that motivates them to come as well...” H2, India.

While our non-U.S. participants even had mechanisms for motivating the follow-up, our U.S. participants had much more limited procedures in place for the follow-up. In the U.S., the follow-up primarily only happened within the settings of private companies who provided the follow-up in the form of insurance to fix the device and give customer support to recipients:

“The way we do it [the follow-up] is we offer a 1-year warranty right out of the gate [...] So if anything breaks in there, we fix it [...] we know who ordered what devices, [...] we have files on everybody. We have all their data. What we'll do is we'll wait for a certain amount of time and call them up and check in and see how it's going” M6, USA.

The few U.S. participants who conducted follow-ups outside insurance policies, appeared to do follow-ups because it was convenient. For instance, the following U.S. participant discussed how the only follow-up he had ever conducted was to a recipient who lived close to him:

“...Well, not extensively [have I been involved in the follow-up]. I have one recipient in particular who's local here, who I've been working with for several years. And I do have ongoing contact with him. So, I know more about how he's using his devices. But, for a lot of the other folks [recipients] I haven't been involved as much in the follow-up...” M8, USA.

The limited availability of follow-up leads some of the recipients in our study to start to become makers to adjust and fix their devices themselves:

“... couldn't hold a spoon [with the device]. Could grip, but not eat with it. Went to the dollar store. Tried Velcro, PVC pipe. I would put the Velcro on the hand and on the end of that PVC pipe. And I'd put the fork inside that PVC, and that worked quite well at first but it just wasn't strong enough. Then got magnets. Oh and the magnets worked so well. Got bar magnets and good glue and I glued the magnet to the palm of the hand [3D printed device]...” R1, USA.



Figure 3. Example of the device adaptation one of our U.S. recipients made for himself by actively becoming a Maker.

Fig. 3 shows an example of the device modifications R1 did to his 3D printed hand. One of our recipients in Mexico (particularly R9) expressed that she had also become a maker to more easily modify her device without needing to involve third parties. However, in difference to the US, usually other family members also got involved:

“... It is usually the women, like my mom or other moms who become makers to help their kids...” R9, Mexico.

Figure 2 presents an overview of the different types of follow-up each of the recipients in our study received, and contrasts with how much the recipient used her device and her level of satisfaction with it. Each point in the graph represents a recipient (or in some cases a group of recipients with similar device usages and perceptions). The X-axis shows the number of years the recipient used her current device and the Y-axis shows the recipient's satisfaction with the device in a six-point likert scale. We note that the recipients who did not receive follow-up in general were clustered in the 0,0 point. These recipients did not use their device at all and, hence, could not even comment on their level of satisfaction with the device. We note from Fig. 2 that there were some U.S. recipients who, even without follow-up, were able to use their device longer term and were overall satisfied with their devices. However, all of these recipients (in specific R1 and R3) were also makers and as a result could directly engage in modifying and adapting their device to cover their needs.

From Fig. 2, we note that the usages and satisfaction that recipients had with their devices varied across participants. It is not clear the type of follow-up that was most effective for long term use and satisfaction, e.g., participants who were co-located in the same region, accessed the same type of follow-up, and had similar device manufactures reported different usages and satisfaction (see e.g., R9 and R4). Similarly, we note that U.S. participants who did not access follow-up but became makers reported longer term device use and satisfaction. Future work could study via controlled experiments the type of follow-up that is most effective on different types of recipients.

5. Discussion

Prior research has started to study makers, recipients, and healthcare practitioners in the ecosystem [1,4]. However, it has primarily focused on the U.S. and Canada [3,5]. The findings from this prior research has raised some concerns because it has highlighted that medical professionals are rarely heavily involved in 3D printed A.T., which could affect the long-term success of the ecosystem [3]. In this work, we study how makers, healthcare practitioners, and recipients in other parts of the world operate. By studying how communities of the ecosystem operate in different countries, it helps us to remove our blinders and begin to see the benefits of involving participants from a more diverse set of countries. Our research helps to highlight the need of further studying the ecosystem with a more diverse set of perspectives (as this can help us to better identify the longer-term needs and gaps of the ecosystem). Through our study, we identified that our U.S. participants followed the patterns that prior research had also found [19]: U.S. makers and recipients generally work independent of healthcare practitioners. However, we also identified that in other parts of the world such setup was not always typical. All of our non-U.S. participants had detailed procedures for involving healthcare practitioners from the start to help in the design of the A.T. and provide quality medical follow-up for recipients. It is currently unclear exactly why outside the U.S. our participants were able to integrate healthcare workers in their operation or why our U.S. participants struggled to do so. Future research could focus on studying how socio-political and cultural differences influence how people organize to produce 3D printed A.T. It is also important to note that makers of 3D printed A.T. tend to have a “fail fast and take risks” attitude that can conflict with a “do-no-harm” oath that healthcare practitioners usually must abide by [21]. It could then be useful to understand how others have been able to bridge the gap and incorporate more healthcare practitioners into the 3D fabrication process. Related, it is likely that our U.S. participants did not do follow-ups because follow-ups are generally associated with the responsibility of healthcare

practitioners. Given that our U.S. participants rarely worked with healthcare practitioners, they were probably not aware of the responsibilities they had after they delivered the devices, and as a consequence they likely also lacked the resources to even do follow-ups (explaining why some of our U.S. participants could only afford to do follow-ups if the recipients lived close to them or if it was included in the insurance of the device). Future research could explore further interviews to better understand the motivations and perspectives of healthcare practitioners in other countries to start to better comprehend what might have facilitated their involvement with 3D printed technology. Additionally, although researchers and practitioners might have been worried about U.S. makers not engaging as much with healthcare professionals, it is unclear how this setup actually affects the quality of the devices produced. Future work could investigate how the different types of participation of the involved actors translates to device adoption. It is currently unclear whether certain operational setups are safer than others for recipients. Particularly, it is unclear whether the regulatory structure in the U.S. is serving to protect recipients or whether it is hurting their medical needs. Future work could explore how these different setups affect recipients, and the ecosystem long term.

Non-use and Abandonment. Through our study we uncovered that recipients engaged in different types of usages with their device and had different satisfaction levels. While the recipients who abandoned their device were the ones who did not receive follow-up, we also note that there were some recipients who even without follow-up managed to learn how to fix their devices themselves and accommodate it so it could cover their needs. Future work could focus on studying the type of dynamics between recipients that lead to longer term adoption. With our study, we took a first step to shed much needed light into the ecosystem of 3D printed AT.

Design Recommendations. Not all our participants integrated follow-up in their operation (especially our U.S. participants.) We believe there is value in designing “Do-It-Yourself (DIY) toolkits” for fabricating 3D printed A.T. that integrate mechanisms through which makers not only receive guidance on how to fabricate the device, but also on what makers should do after they deliver the device (guidance on how to conduct follow-up with medical assistance). We also expect that these toolkits will incorporate the design guidelines that Hofmann et al. [19] proposed for clinical-CAD tools, such as ensuring the tools are easy for any regular maker. Through our interviews we also observed that our participants rarely mentioned working with people from other countries. We believe there is value in facilitating cross-country collaborations. Especially because, as our interviews uncovered, communities in certain countries might have more advancements in certain areas that others could benefit from (for instance, the U.S. communities could benefit from learning about how Brazil does follow-up.) We thus propose to have an “Opensource Storehouse for International Collaboration” where related communities from different parts of the world are connected, and the strengths of each international community in the ecosystem is highlighted via badges. In this way, communities could be able to easily visualize what others are doing well, and identify opportunities to learn from each other.

Limitations. Our research is a snapshot in time of the ecosystem of those involved in 3D printed assistive technology. As time passes the ecosystem around the world continues to grow and evolve. Hence our study only reflects the attitudes, opinions, motivations, and goals of those interviewed at a specific moment in time. In addition, like any study dependent on volunteer participants, our participants' opinions may be biased by self-selection. We were also not able to obtain equal number of actors from each region given the difficulty in connecting and finding these global actors. However, given that previous research had not been able to understand how the ecosystem functioned outside the U.S., we considered our study to be a step forward in understanding how the ecosystem functioned in other countries and the differences that exist across them. Future research could also include more voices from other countries.

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