Health, care and prosthetics: co-design methodologies in the case of Autofabricantes

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Abstract

"Autofabricantes" is a participatory design collective that started at the Medialab Prado in Madrid in 2015. Its main aim is to co-design assistive devices and limb prostheses for children. Combining different types of experience and knowledge, engineers, designers, occupational therapists, and children have contributed to the creation of open source solutions. The following article analyzes this initiative focusing on how design-based strategies have helped to overcome different interests, types of knowledge and legal frameworks (Lafuente and Corsin, 2010) to create an open archive of different solutions and prostheses that can be replicated globally in fablabs or by local communities. By disentangling the material and technical elements of affective and aesthetic decisions, we will argue that the transformation of children into designers of their own members has contributed to empowering these communities and naturalizing a set of prosthetics (Callon and Rabeharisoa, 2002). These artifacts and methodologies work as an answer to some of the problems that market-driven initiatives have not solved (Simonsen, Scheuer and Hertzum 2015). Until now, the market offers invasive and expensive designs over which the people concerned have no decision-making capacity or say.

The paper will analyze a specific set of workshops, examining the protocols, steps, and strategies developed in order to create an atmosphere that allows for the collective design of complex sociotechnical artifacts (Corsín, 2014). It will also analyze how these workshops have given rise to increasingly imaginative products that challenge conventional ideas about how prosthetics and the body itself work and should look like. By introducing children into the design and production process, we can see the emergence of prototypes that go beyond function. This opens debates on how health, care, well-being and design are intertwined and materialized in specific material products to improve the quality of life and social justice (Constanza-Chock, 2020, Bordeleu, 2020).

Author keywords

Prototyping, prosthesis, co-design, care, health, children.

Introduction

"Autofabricantes" is a participatory design collective which started at the Medialab Prado in Madrid in 2015 whose main aim is to co-design assistive products and limb prostheses for children. Combining different types of experience and knowledge, engineers, designers, occupational therapists and children have contributed to the creation of open source solutions (Abad, 2016). The objective of the following article is to understand the role of the children who participate in these workshops as co-designers of their own prostheses. To do this, we will evaluate the methodology used in a specific workshop, looking at the background, previous steps and established dynamics to facilitate the conversion of what healthcare treats as "patients" or sick people into active subjects in the design of their own prostheses. This type of workshop follows the logic of what has been called "DIY prosthetics" (Knochel, 2016) and is integrated into the logic of what is called "critical making" (Record, Ratto, Ratelle, Ieraci, & Czegledy, 2013), that is, the use of fablabs in spaces of collective design or at the service of social transformation.

Background

The "Autofabricantes" working group originates from a first group called EXando una Mano, located in Seville in 2013. This group has developed a set of tactics and methodologies for creating prostheses where users are at the center of the design process. Users, mainly children, are part of a large group of organized citizens who develop them by contributing their expert, experiential or amateur knowledge (Estalella A., Rocha J. and Lafuente A, 2013). The workshops that we are going to analyze take place in Medialab Prado, a space for public cultural experimentation or citizen laboratory (Corsín, 2014). This space was and is a pioneer in opening of conceptual debates and hybridization of disciplines, areas of interest and democratization of possibilities for innovation and research with and from citizens (Fabian and Rowan, 2016). In a broader scenario in the European context almost two decades have past since the inception and development of communities dedicated to the creation of free and/or self-built hardware, and the appearance of fablabs, makerspaces, etc. This has contributed to many changes in the ways objects are being designed and produced (Perez de Lama y García, 2018). Recently specific communities have grown around concrete needs and concerns, such is the case of

communities of concern around health issues. This has contributed to blend fablabs and social concerns (García, 2019). Currently there are many collaborative design communities with disparate formats of collaboration, organization and management (Fanio, Jimenez-Martinez, & Cantero, 2020). At the same time, and in the opposite direction, we must acknowledge how the public health system considers that the individual who is missing a limb is a patient who needs to be treated and cured.

For the health system, the individual citizen becomes the responsibility of the State, or of him or herself. By doing so the problem becomes individualized and the subject reduces his or her agency (Stengers, 2005, Bordeleau, 2010). The disease is cataloged and individualized, and treated through a series of standardized and regulated protocols in the search for a maximum care guarantee for the general population. This situation has resulted in a pathologization of a multitude of personal situations that, in part, have social and contextual components (Segura 2018). The theories surrounding functional diversity challenge these standardized assumptions of what health and wellbeing imply (Toboso, 2018). In the context of digital manufacturing workshops, so called patients are transformed into active subjects on the design of their own prostheses.

Over many decades, the health and pharmatheutical sector has responded to this question by providing a wide variety of technical solutions (such as prostheses or ortho-prostheses) that provide disabled users with tools to function "normally". The aim is to make all of the bodies equal, adapting to a capable and normative body (Agulló, 2011). A large catalog of technical assistance devices have been created to which the disabled user should adapt without questioning the specificity of his or her disability in order to fully relate to the world. The person affected is almost never a participant in the functional, aesthetic or formal decisions of their technical assistance: most of the time, it is their bodies that must adapt to them (Cottam 2019; Driedger, Kothari, Morrison, Sawada, Crighton, & Graham, 2007). In recent years, many collaborative project initiatives of different modalities, durations, and depths have emerged to provide concrete responses to this lack of adaptation, debate, and/or care models in the orthopedic and prosthetic market.

Case study

Within the trajectory of Autofabricantes, in the period that goes from 2015 to 2020, the collective operated as an open research group with about 20 permanent members and another 30-40 volunteers that took part on an occasional basis. These members contributed with their specific knowledge in some part of the development of different prosthetics (electronics, industrial design, programming, occupational therapy, manufacturing, physiotherapy, etc.). Citizens from different backgrounds were organized following thematic subgroups and met weekly in person at Medialab Prado. These sessions included families and children with missing limbs, and previous experience in the use of market produced prostheses. The technical documentation derived by

these workshops can be found in Github's own repositories[1] or on the Medialab's site[2]. Based on this work and creation system, a string of different projects have been developed. All stem from proposals put forward by the children to the working group. This made it easier to address questions that the children themselves asked, such as "Why should a hand look like a hand? or why should a prosthetic tool respond to a specific need and not to the complexity of a common hand. In the following paper we will address the creation of a specific prototype named "SuperGiz", a prosthetic glove that can be adapted and modified to a variety of bodies and playful needs.

Methodology

In the following paper we will focus on the analysis of a workshop that helps to develop the SuperGiz prototype. The workshop took place between March 7 and May 5, 2022, and it is the last in a series of workshops that took place during more than 4 years. We chose to focus on this specific workshop because it is the most recent and the first to take place after two years of the pandemic. This is also the first workshop to include improvement of life quality protocols. These protocols were approved by the ethics committee of the VIC University.

We will focus in these specific points:

- » What are the important elements that affect the degree of participation of children in the design of their own prosthesis.
- » Which are the tools or means used in these workshops.
- » How the participant children blend and are able to collaborate with their working group.
- » What is the degree of satisfaction and frequency of use of the prototypes the users designed.

In order to carry out this research, we proceeded as follows:

- » Description of a research protocol, ethical code, data collection code based on WHO regulations, national and European data protection law and data collection notebook guidelines (Braun, Clarke 2006).
- » Approval of the protocol by the University of VIC with a defense and rectification of improvements by the evaluating committee.
- » Review of the internal evaluation reports generator by Autofabricantes and proposal for improvements.
- » Implementation of the workshop with improvements already foreseen in the protocols and in the internal evaluation reports.
- » Guided observation and description by the researcher of the behaviors of the children, their family and their group based on a data collection notebook with the above objectives, among others (Estalella and Corsín, 2020)
- » Brief survey on the degree of participation and group membership.
- » Comparative description of the changes introduced into the workshop structure and the consequences they had with respect to previous workshops.

With this we hope to disentangle the material and technical elements of affective and aesthetic decisions, showing how this project has helped to transform children which the health system considers to be patients into the designers of their own prosthesis.

Key aspects surveyed

Time

Each workshop takes place over three months of time with three moments of intensive work separated by one month each. A first contact workshop in which a free prototyping of ideas takes place is followed by a second workshop based on testing, redesigning and adaptation of these first prototypes. The third workshop focuses on testing, reviewing and certifying usability. Between each session, the collaborating teams design and 3D print each model that is tested in the workshops. The interval of three or four weeks between each workshop is adequate for the development of the designs and on the other hand the links between participants are not diluted. The communication between members of the workshop does not stop during this time and details, questions and progress reviews get shared.

The sessions always take place on Saturday mornings to facilitate travel (many families and children come from other parts of Spain). In the workshop we surveyed, the second session was on a Friday afternoon due to the Medialab agenda. We observed that they were visibly more tired, more focused on resolving the design challenges and less time spent on conversations or social interactions after the workshop. A regular session lasts about two hours (from 11 a.m. to 1 p.m.) and in more than 80% of cases it is extended by another hour due to dialogue among participants. Friday's session barely lasted 1 hour and 30 minutes (from 5:00 p.m. to 6:30 p.m.) and there were even families that arrived late or left before the scheduled time, the collective time was barely 50% of that scheduled.

Preparation

Participants need to contact the organization and request to take part in the workshops. They are sent information regarding health and safety protocols and information on ethics and data management in order to comply with the ethical research standards. In the internal evaluations of the workshops, we detected that some children arrived with a high level of suspicion and without a clear idea on the nature of the workshops they were going to attend. Therefore, the transmission of information from parents to their children was not effective. From that moment on, families are provided with informative videos and guides that they can show their children. In this way they do not generate false expectations, they know the environment, possibilities and limitations of the workshops, what kind of people they will meet, etc. Their role as active agents in the work process is also explained to them. With this their adaptation to the team is faster.

Managing expectations is a key element throughout the design process. The children are between 5 and 12 years old and in 70% of the cases (own interviews with 20 cases) they have already used another type of prosthesis that has not worked

for them. In the first workshops the expectations were high: they proposed to solve at least 4-5 activities and they did not know that in the first two sessions there would be failures and problems regarding the prototypes designed. Currently they are asked to bring only 2 ideas of activities to design (this can change over the workshops). They are also advised that some of the prototypes may not work or need to be resized or redesigned. It is essential to shift attention to effectiveness at the time of testing to eliminate as much frustration about functionality and gain insight into the process. In the analyzes to improve the quality of life that we carried out, we can see how 18 cases, the result is 3 out of 3 in priority activities and 2-2.5 in non-priority activities. (see table 1)

Table 1. SuperGiz assistive devices: frequency of use and satisfaction throughout the study (n = 18).

	T_1	T_3	T_6	
	Median (Q1-Q3)	Median (Q1-Q3)	Median (Q1-Q3)	p [a]
Activity chosen as priority				
Frequency of use	2 (2-3)	2 (2-3)	2 (2-3)	0.607
Satisfaction level	3 (2-3)	3 (2-3)	3 (2-3)	0.368
Non-priority activities (n = 17)				
Frequency of use	2 (1.25-2.45)	2 (1.12-2.50)	2 (1.37-2.55)	0.513
Satisfaction level	2 (1.75-3)	2.5 (2-3)	2.5 (2-3)	0.165

T1, one month after finishing the SuperGiz collaborative workshops (baseline); T3, three months after baseline.; T6, six months after baseline.; Q1, first quartile; Q3, third quartile.   a Friedman´s test.

Spaces

Although it may seem like a less important aspect, we must acknowledge how space shapes and conditions workshops and studio practices (Farias & Wilkie, 2016). It enables conversations and cooperation which are key elements to establish shared aims and objectives. In the workshops we simultaneously found 5 teams of 5-6 people plus the main production team of Autofabricantes and some invited people, a total of about 40 people. It is a non-medical place, with tables, chairs and rapid prototyping tools.

Some of the most relevant aspects and changes introduced in the last workshop were, for example, the introduction to a small space prior to the workshop room. On the first day, children and parents are received by a workshop leader from the Autofabricantes team. This welcome with few people generates a first moment of complicity and trust, out of the sight of many adults. Guided by a small protocol, in 15 minutes they get to know each other, the whole design process is outlined, and the participants get to touch and see examples of other designs done by other children. During the interviews conducted we discovered that part of the frustration, anxiety and generation of false expectations is derived from the conversations between parents and their children (80% want a prosthesis similar to a hand, functional and with full adaptation for their child). In addition, we detected that 50% of the families do not know other families in the same situation. To facilitate interaction between participants breakfast and drinks are provided. This helped to promote informal interactions and conversations that contributed to promote trust among participants. To increase interaction, in the last

workshop the central table of the space was for breakfast. The fact that the Autofabricantes team is not present in this context has led to riskier design decisions and proposals as shown in internal reports.

We must also note that along all the design phases, basic tools are needed to fasten the movement from ideas to prototypes. Colored pencils, cardboard, paper, scissors, plasticine and other basic tools are widely available. In this workshop we noted that all the tools except pencils and paper have been centralized on a table (next to the breakfast) so that children can freely go for what they need. This change has two objectives: to increase proactivity and to help shy children to interact with their peers. All this has been reported by the Autofabricantes team in the last evaluation report after the workshop.

Roles and interaction

From the very beginning each family unit is accompanied by a team of four collaborators composed by someone expert in engineering, industrial design, physiotherapy or occupational therapy. This team is the reference point for the child and the family. For 3 years they have been given specific training on interaction in order to build-up the child's confidence. They propitiate playful interactions, use simple and clear vocabulary, help with prototyping, etc.

A member from the Autofabricantes team is the person of reference for each design unit. Their main task consists in helping to generate bonds of trust amongst participants and children. This person also conducts the workshop, is the timekeeper and keeps in touch with the family after the workshop finishes. This person also provides the general design criteria and helps to define the limits and the possibilities of manufacture, use, etc. Other adults with a missing limb are sometimes invited to meet the children and their families. This idea was first proposed by one of the attending families and we have detected that it is important in order to naturalize different disabilities and have other references to look at.

The workshop itself

Session 1: The initial welcome and introduction to the general workshop dynamics is crucial for the children attending the workshops. Afterwards, they begin to design the possible solutions to the problems posed using quick prototyping options such as paper, plasticine and cardboard. They draw, touch and each participant contributes with ideas or prototypes. Sometimes they can play with objects, attaching them to their arm, or drawing directly onto their bodies. When the definition of the designed solution advances further, a first conversation about materials and technical challenges takes place. Each step, the child is made aware of the possibilities or limits of their design.

Session 2: In this session the team focuses on lowering the child's expectations. On this stage 3D printed prototypes and models to test are available and in more than 50% of cases they do not work for reasons of size or adjustment. The biomechanical conditions here need to be taken into account. The team (including the children) pay more attention to every detail, re-measure and intervene or modify the

physical model in situ to test changes or new ideas. Touching the models contributes to arriving at better design solutions to which the whole team can contribute.

Session 3: This last stage is all about testing out the prototypes. If all the designs fit and have validation from the occupational therapists, they can take them home. In evaluations of previous cases, we detected that the parents determine in a clear way the frequency of use of the prosthesis designed by the children. To reinforce the degree of commitment of the children, a card with 4 simple use guidelines is included along the prosthesis. A space was also added with a handwritten message from the work team, thus also reinforcing commitment and affective ties through the group.

Evaluation and conclusions

In order to know the perception of the children about their participation in the design process and their belonging to the working group, a brief questionnaire was introduced into this workshop. It was carried out with the presence of their parents, in the final 30 minutes of the workshop. The children read and answered directly on a scale of 1 to 5 to 6 questions. 5 families took part in the workshop and 4 children answered. The questions and results, in this order, were the following:

Table 2. Children perception about their participation

	Yes	No	1 / little	2 / rather	3 / normal	4 / quite	5 / a lot
Do you like your SuperGiz?	4	0	-	-	-	-	-
Do you like to do things in a group?	-	-	0	0	0	1	3
Have you participated in designing it?	4	0	-	-	-	-	-
How much have you participated?	-	-	0	0	1	1	2
Did you like doing SuperGiz in a group?	-	-	0	0	0	2	2
Do you consider yourself part of the group?	-	-	0	0	0	1	3

Acknowledging that the sample only corresponds to one workshop and only a few children replied, we can highlight an adequate response regarding one of the objectives of the workshops, enjoyment and in a minor degree, participation. More research needs to be conducted but after following this project we can conclude that these workshops have contributed to a big degree to transform children into the designers of their own prostheses. Many factors have contributed for this to happen: methods, tools, work rhythms, spaces, materials and conversations. Another key element identified in this process is the creation of trust among participants. Children must increase confidence in their skill and build trust with their group.

We also consider it important to note that in this program any design carried out must be thought from a particular need but must serve many more people, this implies rethinking versatility, changing parameters and including other

families and groups in the design process. Children go from designing only for themselves to design for others. Knowing that disabled children can prototype almost anything relatively quickly allows them to imagine more possibilities and re-think completely how a prosthetic limb should work and look like.

The introduction of celebrations after each important design milestone helps to build the child's confidence in their skills as a designer. Building networks of trust along different generations, persons with different skills and knowledge is key for these workshops to function. Definitely this project has developed interesting strategies to promote collaborative and participative ways of designing and empowering the children that attend and are the central agents of these workshops.

References

Abad, David. (2016). Una etnografía de la participación ciudadana en la producción de conocimiento científico y tecnológico.

Agulló, C. (Ed.). (2011). Cojos y precarias haciendo vidas que importan: Cuaderno sobre una alianza imprescindible (Primera edición). Traficantes de Sueños.

Bordeleau, E.(2020): El cuidado de los posibles, Una conversación con Isabelle Stengers. Ed. Cactus. [Interview]. https://editorialcactus.com.ar/blog/el-cuidado-de-los-posibles/

Braun, V., Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2), 77-101, DOI: 10.1191/1478088706qp063oa

Callon, M & Rabeharisoa, V. (2002). L'engagement des associations de malades dans la recherche. Revue internationale des sciences sociales, 171(1), 65-73.

Costanza-Chock, S., (2020). Design justice: community-led practices to build the worlds we need. MIT Press.

Corsín Jiménez, A., 2014. Introduction: The prototype: more than many and less than one. Journal of Cultural Economy 7, 381–398.

Cottam, H. (2019). Radical help: How we can remake the relationships between us and revolutionise the welfare state. Virago Press.

Driedger, S. M., Kothari, A., Morrison, J., Sawada, M., Crighton, E. J., & Graham, I. D. (2007). Correction: Using participatory design to develop (public) health decision support systems through GIS. International Journal of Health Geographics, 6(1), 53. https://doi.org/10.1186/1476-072X-6-53

Estalella A., Rocha J. y Lafuente A. (2013). Laboratorios de procomún: experimentación, recursividad y activismo. Teknokultura. Revista de Cultura Digital y Movimientos Sociales, 10(1), 21-48. https://revistas.ucm.es/index.php/TEKN/article/view/48053

Estalella, A. Corsín A. (2020). Acompañantes epistémicos: la invención de la colaboración etnográfica. 145-169.

Fabian, L., & Rowan, J. (2016). Retweet this: Participation, collective production, and new paradigms of cultural production. In Intellectual History of Economic Normativities. https://doi.org/10.1057/978-1-137-59416-7_14

Farias, I., & Wilkie, A. (Eds.). (2016). Studio studies: Operations, topologies and displacements. Routledge, Taylor & Francis Group.

Fanio, A., Jimenez-Martinez, C., & Cantero, J. D. L. T. (2020). Los Fab Labs como laboratorios de creación para la inclusión social. https://doi.org/10.13140/RG.2.2.15585.94568

García, C (2019). Fabricación digital, movimiento maker y futuro del trabajo. Fundación Orange.

Knochel, A. D. (2016). DIY Prosthetics: Digital Fabrication and Participatory Culture. Art Education, 69(5), 7-13. https://doi.org/10.1080/00043125.2016.1201401

Lafuente, A. & Corsín, A. (2010) "Comunidades de afectados, procomún y don expandido" Fractal (México), 57: 17-42

Pérez de Lama, J, & Garcíaz, c. g. (2018). Comentarios sobre la fabricación digital distribuida –makers y fab labs– y economía colaborativa. en economía colaborativa... ¿de verdad? (pp. 79-139). ediciones laborum.

Record, I., Ratto, M., Ratelle, A., Ieraci, A., & Czegledy, N. (2013). DIY Prosthetics Workshops: 'Critical making' for public understanding of human augmentation. 2013 IEEE International Symposium on Technology and Society (ISTAS): Social Implications of Wearable Computing and Augmediated Reality in Everyday Life, 117-125. https://doi.org/10.1109/ISTAS.2013.6613110

Segura, J. (2018) Comunitaria. Ediciones Salud pública y otras dudas.

Simonsen, J., Scheuer, J. D., & Hertzum, M. (2015). Accreditation and Participatory Design in the Health-Care Sector. In A. Öörni, K. Kuutti, H. Oinas-kukkonen, & M. Rajanen (Eds.), Proceedings of the 38th Information Systems Research Seminar in Scandinavia (IRIS 38) IRIS.

Stengers, I. (2005). Introductory Notes on an Ecology of Practices. Cultural Studies Review, 11(1), 183–196. https://doi.org/10.5130/csr.v11i1.3459

Toboso Martín, M. (s. f.). «Diversidad funcional: Hacia un nuevo paradigma en los estudios y en las políticas sobre discapacidad», en Política y Sociedad, 55(3), 2018, págs. 783-804. En Política y Sociedad.