Design for vunerable community: the oppressed point of view

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This paper described the path of Vila Rosario project that had its roots in empathic design, but finally built on Paulo Freire's Pedagogy of the Oppressed. The study was conducted in 2005-2008 in Vila Rosario about 20 km north of downtown Rio de Janeiro. It focused on the prevention and treatment of tuberculosis. The paper describes our design approach, process, drivers, many design outcomes, and our tests. It ends with a discussion of the implications of our approach to design.

Keywords: Empathic Design; Design for Wellbeing; Constructive Design

Vila Rosario

This paper described the path of Vila Rosario project that had its roots in empathic design, but finally built on Paulo Freire's Pedagogy of the Oppressed to reflect its Brazilian roots. Its subtext is how research provided evidence that pushed the designers away from the original brief's high-tech focus to develop a series of low-tech designs.

The study was conducted in 2005-2008 in Vila Rosario about 20 km north of downtown Rio de Janeiro, and was done by two Brazilian designers, who worked with local doctors and health agents (more about this term later). The aim of the project was to help these front line health care workers to combat tuberculosis, which was a main killer in the community. Over the course of the project, the designers researched the main ways of contagion in the community, created designs health members of the local community could use to teach how TB is contracted and how it can be treated, tested these designs, and finally implemented with using a mesh of traditional and new technologies. According to the original brief, the

study was to develop hi-tech solutions to social problems, but at the end, the project put stress on traditional technologies.

Vila Rosario is the name the Society of Fine Chemistry to Fight Against Tropical Diseases (QTROP) gave to designate an area larger than only Vila Rosario's neighborhood. They call the area "The Great Vila Rosario." It is situated between the rivers Sarapui and Iguaçu, and it is connected to the Rio de Janeiro downtown area to Guapimirim and west with the Belford Roxo Municipality by railroad (Costa-Neto 2002). Administratively the area is located in the second district of the city of Duque de Caxias (region of Gramacho).

Figure 1. From the front of Instituto Vila Rosario. Health Agents are on the left side on the sidewalk.

Figure 2. Some of the wetlands in Vila Rosario. Lush growh benefit from heat and nutrition-rich water.

Vila Rosario is in the middle of a tuberculosis epidemic. Government statistics show an alarming incidence of tuberculosis of 103 cases per 100.000 inhabitants. Vila Rosario has the same problems as many other rural communities: no access to economic opportunities, and little access to basic utilities and services such as running and clean water, high-quality public education, and health care (Costa-Neto 2003).

The project Vila Rosario built on empathic design (cf. Mattelmaki et al. 2014), which gave it is basic worldview of people as meaning making creatures who author their own lives (see Battarbee 2004), and methodic tools for empathizing with people in the community (Koskinen et al. 2003). However, the project soon faced the limits of empathic design. It had historically focused on understanding emotional user experience of ICTs, while in Vila Rosario, the main sources of health problems were social, including illiteracy, poverty, and lacking infrastructure.

To go beyond from empathic design, Vila Rosario picked up its main cue from Pelle Ehn's early work in participatory design (Ehn 1988: 9). He mentions in an important footnote that early participatory design was inspired by Paulo Freire's participatory critical pedagogy (Freire 2005). For us, Freire gave a design process that situated our research efforts into the community and helped to integrate local and scientific knowledge. He also gave us a stepwise process to work with community response to tuberculosis.

Design for the oppressed

Paulo Freire's pegagogy gave a process and a tried method for Brazil (see also Couto and Ribeiro 2002; Cunha 2005). Following Freire, we had to start with what people from the community already know about their own village. This was the precondition of finding ways to conscientização (conscientization), a process of making people better aware of their reality to change it to take their own humanity into account:

> *The oppressed, a pedagogy which must be forged with, not for, the oppressed (whether individuals or peoples) in the incessant struggle to regain their humanity. This pedagogy makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come their necessary engagement in the struggle for their liberation. And in the struggle this pedagogy will be made and remade. (Freire 2005: 48)*

If a designer is willing to learn from the community, he may become a co-investigator who can deepen the community's self-knowledge. The tool for this is a project that instigates curiosity and it helps the community to discover new ways of thinking about their "thematic universe." This, in turn, is a precondition to engagement and commitment to change.

Following Freire's democratic philosophy, it is important to share the dialogue and to share the world with others. Fundamentally, design for the oppressed helps people to know their reality by sharing their life histories, their knowledge, and their understanding of their ways of interpreting reality. Designer should also let the community to change her own values, ideas, attitudes, and behaviours by introducing her to the families, social groups, schools and other groups who maintain the realities that shape the community.

Ultimately, a successful project helps both parties to see their lives in different ways and to think and talk about issues that they previously would not thought or talk about.

The instrument to change is dialogue. A genuine dialogue begins when the researcher asks herself what she will do in that community. It starts when she begins to read about the community. It prepares the community to research. It also prepares the researcher to encounter the community. Finally, it prepares both parties to understand others' premises:

The pedagogy of the oppressed, as a humanist and libertarian pedagogy, has two distinct stages. In the first, the oppressed unveil the world of oppression and through the praxis commit themselves to its transformation. In the second stage, in which the reality of oppression has already been transformed, this pedagogy ceases to belong to the oppressed and becomes a pedagogy of all people in the process of permanent liberation. In both stages, it is always through action in depth that the culture of domination is culturally confronted. In the first stage this confrontation occurs through the change in the way the oppressed perceive the world of oppression; in the second stage, through the expulsion of the myths created and developed in the old order, which like specters haunt the new structure emerging from the revolutionary transformation. (Freire 2005: 54-55)

This approach puts the focus on the community's self-understanding, but also situates it to expert knowledge. He also taught us to be wary of treating ourselves as experts in our interactions with an underdeveloped community. Here he is well in line with our inspirations in empathic and participatory design, but he also gave an ethic of respect. Rather than teaching it better ways, this ethic told us to find ways to add quality and mutual respect to our interactions with our invisible community.

Our approach remained indifferent voices that urge us to create agonistic designs to initiate conscientização (see for example Markussen 2011; DiSalvo 2012). Our approach was more akin to community organizing and Brazilian social design (Couto and Ribeiro 2002: Cunha 2005) and some streams of participatory art (see Koskinen 2014).

1. Search and analyse secondary data
2. Go to the community, recruit locals to assist in design, and get immersed in data
3. Identify themes key to understanding the community and its problems
4. Iterate and return to the community until the understanding is robust enough to be accepted by the community
5. Create didactic materials with instructions and study these with the local community

Table 1. Design for Hope, inspired by Paulo Freire

Making sense of Vila Rosario

The first steps of Freirean pedagogy aim at making the resarchers wary of imposing their own visions on people studied. They need to familiarize themselves with the community being studied and make sure their understanding is robust enough to form working base for designs to come.

ASPAS and IVR

First we did desk research and conducted a literature review. We also benchmarked Web sites for health care and for Brazilian content. In addition, we red Dr. Costa-Neto's studies about Vila Rosario and consulted doctors to learn about tropical diseases (Costa-Neto 2002, 2003, 2004).

ASPAS is an ambulatory supported by the Catholic Church, that brings some relief to Vila Rosário (Figure 3.9). ASPAS allowed Instituto Vila Rosário (IVR) to use its facilities until 2008. Our main informants Drs. Castello-Branco and Costa-Neto told us about the history of the institute (also Costa-Neto 2004):

> *In 2004, they had a meeting at QTROP (a Chemistry Society for fighting Tropical Diseases) where 31 participants from QTROP and from Vila Rosario took part. Together, based on some criteria and diagnosis, they did a list of 20 potentials activities to be chosen by people from the community to be approached in the workshops. After this step, they submitted the list to community members. The majority of the interviewees wanted to be enrolled in the courses related to sew, embroidery, and related courses (all females), herbalism, mosaic, wood and ceramics. They started the program based on the community feedback. On the first day, there was an embroidery, sewing and textile workshop. From the 72 women enrolled, just one came to the course, and she came with her child (Field note).*

The process of inhabitants being committed to a project like this is very slow process. In their opinion this situation is comprehensible, as a process like this requires new habits. Inhabitants often are not ready for changes. But when they see their neighbours, taking part on the courses, afterwards earning money, and as consequence, changing their habits and improving their lives, they start to get involved in the projects.

Field studies in Instituto Vila Rosario

After desk research, we used several techniques familiar from empathic design (Koskinen et al. 2003; Mattelmaki 2006). First we created a series of cultural probes that were administered by our friend who assisted us at this stage of research (see A. Judice 2014; M. Judice 2014). Following Mattelmaki's example (2006), we wanted to check whether our interpretations of the probes were correct. In contrast to her interview-based studies, our check was ethnographic fieldwork. This fieldwork consisted of a three month stay in the village, during which time we got familiar with ASPAS and IVR, health agents and some villagers.

The health agents work to Instituto Vila Rosario, but Ataulfo de Paiva Fundation – FAP pays them. The FAP was established in 1900 with the name "Brazilian League against tuberculosis", and until today, it is consider by the International Union Against Tuberculosis and Lung Disease as the representative Institution of Brazil. It means that FAP is the Institution that represents Brazil abroad when the subject is tuberculosis. FAP is a foundation with no commercial interests, so the money that the foundation collects is used for works like this intervention in Vila Rosario, or for technological improvement.

Figure 3. ASPAS

Figure 4. Health Agents in 2008

With the FAP grant, IVR hired a group of Health Agents, women recruited from local population. Their job was to be the foot soldiers of the campaign against tuberculosis. They did home visits to search new cases of tuberculosis, to guide in treatment, and to make sure

people go through the entire treatment. Health Agents came from several backgrounds, were of many ages, and had education ranging from elementary school to university degrees. What was common to everyone was that they knew Vila Rosario and its people, and were willing to help in making it better.

There are several workflows in the Health Agent's daily activities, including house-to-house screening process. The main steps described ahead shows a specific search for ill person, called at IVR as "active search". These are some main steps of their work:

- Identification. First the Health Agents identify the necessity to visit a person that has symptoms of tropical diseases or are already ill. Identification can occur through a neighbour, a friend or someone from the family, who can inform to a health agent. Also the information can reach the VRI through gossip, or the ill person may asks for help.

- Mapping. Next Health Agents identify where the patient lives, then they mark the location on the map. These procedures help to identify who is the Health Agent in charge of the area, and also, help to draw the boundaries of the spread of the disease. In this moment the exposure is just a hypothesis, so they will do this procedure again after talk to the patient face-to-face.

- House visit. They go to the house of the ill person. They can go in the same day they reach the information, or they can book another time. Once they have success in speaking to the patient, they introduce themselves and explain their work. If they cannot reach her, they try to contact him again.

- Examination. Then they talk with the person and they try to make a diagnostic of the situation (not only of the disease but about all situation – house conditions, hygiene, nutrition, and so forth). They talk and observe the inhabitants habits – nutrition, job, sustenance, conditions of the house, kind of clothes, etc.

- Initial diagosis. They to identify what kind of illness affects the person and explain to the patient family and close friends the situation. At this moment they use some material to support their work, for example, booklets about illness.

- Cure. They explain the procedures that the patient must adopt before the appointment. They also ask if the ill person has any doubts, stress the importance of the treatment and guide the patient to the treatment. They agree with the patient if they, as community

health agents, will make the follow-up of the treatment. If the patient requires they will monitor the treatment to be sure that the patient and the family are doing everything correctly, and to not stop the treatment too early, which is a real a problem especially in tuberculosis case. The Health agents usually follow the patient until discharge. Some cases the follow up even after discharge.

- Medical records. They fill the VRI form by handwriting to fill the database with patient's personal data, but also add environmental, nutritional and other data.
- Entering research data. They mark in the map which illnesses had been found in the house. This is not a standard procedure, but it helps in mapping the spread and the contagion pattern of the diseases.

Two particularly interesting points stressed by the community health agents were: the support materials they are using now are not appropriate to their work. The material has drawings that are not connected to the community context and the content need to be more connected also to their work. The other point was that they have difficulties to explain all the work they do to the community's members. Sometimes, because people do not know what the community health agents do, they do not even open the door.

Projective techniques in field work

Specifically, we studied information technology and the workings of IVR. When conducting these studies, we also used two projective techniques with health agents to learn what they were dreaming about, Magic Things (Iacucci et al. 2000) and Good Fairies, the latter being our own invention (see Table 2). These techniques revealed us the power of media over local imagination. Especially characters and plots from telenovelas. This became a leading theme in our design program.

After many workshops, inquiries, observations, and other contacts, Health Agents started to get used to our presence. As they were comfortable enough with us, we decided to ask them to try a new experience. We asked them to imagine a Good Fairy, and asked them how the Fairy could help them in their work. When they were telling what they would wish from the Fairy, we also asked them to explain how they think the Fairy could help.

Table 2. How would a Good Fairy help Health Agents

Expert workshops

As Freire adamantly notes, researchers need to build their view of the community not only on local visions, but also on expert opinion. In analyzing our data, we therefore conducted a series of workshops with Brazilian experts to make sure we had access to a broader context than Vila Rosario alone (Figure 5).

Figure 5. Analysing data in Brazil with psychologists, designers and doctors

Design drivers

Based on our studies, we developed two sets of drivers to give structure to our design program. The first set focused on content, the second on form.

Thematic universe as a design driver

Analysis in Freire's pedagogy starts from identifying and describing the thematic universe of people being taught. From our analysis, we selected five themes we wanted to address with our designs. These themes are explained in more detail in A. Judice (2014).

Diagnosis. Health Agents were not trained as medical professionals, and needed help in preliminary diagnosis of illnesses. Many diseases have ambiguous symptoms, which only

an experienced doctor can read. Seeing that a child has diarrhea is one thing; being sure he has tuberculosis in its early stages is much more difficult. Health Agents needed help in recognizing symptoms and writing them down for doctors.

Communication between health agents and doctors. As the first theme suggests, the second theme was communication with doctors. This, we thought, should happen at two levels. First, Health Agents should be able to function as the doctors' eyes, ears and hands in more distant corners of Vila Rosario; to do this, they needed tools to work with patients and communicate their observations and actions to doctors. Second, often when the doctors were not in the ambulatory, they still needed to be contacted. For this communication, we built a Web site.

Persuade patients to pay attention to the symptoms of disease and to take medication. The third theme we decided to address was more didactic. Health Agents needed material they could use to teach the inhabitants about the symptoms of diseases like tuberculosis, and to take these symptoms seriously. When they had been diagnozed, Health Agents needed material to show that the patient needs to go through the whole cure. In particular, this is the case with tuberculosis. Medication helps with the worst symptoms in two weeks, and many patients stop taking the drugs after this period. The full course, however, takes months, and is needed first to cure the disease and second to make sure the disease does not develop resistance to antibiotics.

Hygiene. The fourth theme went beyond medical issues to their sources. There was a need to improve the inhabitants' understanding about the importance of hygiene. Bad hygiene is the root cause of many illnesses, and Health Agents needed material that could show how deficient hygiene breeds illnesses through things like dirty kitchen knives, dirty water, unwashed hands, and lice.

Nutrition. The final theme we addressed was nutrition. Like in many poor neighborhoods, people in Vila Rosario ate lots of high-energy foods that were barely nutritious. In short term, this affected immune systems and led to weaker resistance to many common diseases. The longer-term consequences, however, were more serious. If malnutrition continues for long enough, it leads to developmental disorders; in particular the brains of children may remain underdeveloped, which can be seen in later years in cognitive deficiencies and poverty.

Form drivers

In addition, our fieldwork taught that all our designs had to be

- Low-tech: Vila Rosario was poor and not even electricity was a certainty;
- Easy to reproduce: designs should be easy to reproduce;
- Have little monetary value: installing things like Web kiosks would have been stolen: our designs had to be cheal;
- Colloquial: designs had to speak the language of the community (see Ehn 1988).

Design program

Our design program was built to satisfy these two sets of conditions. Topically, it focused on tuberculosis, its contagion mechamisms, and its relationship to hygiene, and nutrition. It also set the disease into the health care context, showing people how to contact health agents and how to work with them in order to cure the bacteria. Technically, our observations led us to build low-tech and cheap graphic designs using local elements, and play down hi-tech solutions that assumed the existence of a highly developed electronic infrastructure.

Table 3 describes our design program. At the heart of the program was the etiology and treatment of tuberculosis and the community organization that aimed at improving the living conditions of the local population. The table shows our eight designs and their relationship to different aspects of the thematic universe. It also provides a breakdown of the designs by their intended audience, and shows how they relate to our form drivers. The visual identity program was an extra; by providing a clear visual identity to IVR, we aimed at giving the program visibility in the community.

Fictional vila rosario

The fourth step in Freire told us to develop our designs together with people we worked with using language they understand. In our field studies, we had seen how powerful things like telenovelas and comics are in giving shape to local gossip and imagination.

We took our cue again from Ehn (1988), who had borrowed Ludwig Wittgenstein's notions of language games to justify using experience-near design tools instead of abstractions from universities (Ehn 1988; Ehn and Kyng 1992). The first step in our work was creating a design library filled with graphic characters from Vila Rosario. Figure 6 illustrates some characters of the library.

Figure 6. Some characters from fictional Vila Rosario: doctor, local young man, health agent

Designs for healt agents

Most of our graphic designs were aimed at improving quality in interactions between healt agents and their patients. We created posters and tuberculosis booklets in the form of comics. We also created them research tools that could help them to map the disease better for epidemiological purposes. These designs were meant to help in diagnosis, in communicating about the treatments, and in persuading patients to take the medication as prescribed. They also described the ways in which the disease spreads and its early symptoms. Figures 7-8 are examples of these posters, all using our fictional Rosariense as characters.

		DESIGNS							
		Low-tech				High-tech		Visual identity	
		Book-lets	Posters	Games	Work-shops	Portal	Educational movies	Design management	Health agents' kit
THEMES	Diagnosis	+	+	+	+	+	+		
	Communication	+	+	+	+	+	+	+	+
	Persuasion	+	+	+	+	+	+	+	+
	Hygiene	+	+	+	+	+	+		
	Nutrition	+	+	+	+	+	+		
AUDIENCES	Health Agents	+	+	+	+	+	+	+	+
	Doctors					+	+	+	
	Other specialists					+	+	+	
	Senior citizens	+	+	+	+		+		
	Adults	+	+		+		+		
	Teenagers	+	+	+	+	+	+		
	Children	+	+	+	+	+	+		

Table 3. The structure of the design program

Figures 7-8. One of the tuberculosis posters; a poster teaching children hygienic habits; a poster teaching the proper treatment of garbage

The format of the booklets came from an observation telling that children enjoyed comics, but patents seldom had money to buy them to them. With the format, we were also able to communicate causalities in the disease process. Figure 9 shows a comic that taught people about the most typical symptoms of tuberculosis, and about the treatment process. The

message was hopeful though demanding: there is a cure, but to get well, the medicine has to be taken until the disease agent has left the body completely.

Figure 9. From a comic teaching about the symptoms of tuberculosis

Behavioral designs

Two types of designs were behavioral and meant to be put to use by the community rather than by the health agents. These designs were games aimed at children and workshops aimed at young mothers, who were key characters in teaching children to stay in good health.

An example of a game is Lazy Man, which was a card game meant to break down the fear of authorities of various kinds (see Table 4). The game could be played from three up to six players. The dealer deal all of the cards to the players. Some players may have more cards than others. Players look at their cards and discard any pairs they have, face up. At the moment of discarding pairs, the player should describe the profession and why is it good for the community. If he fails to describe the profession, he/she will receive the Lazy Man card.

Game scenario. Beginning with the dealer, each player takes turns offering his hand facedown to the person on his left. That person selects a card and adds it to his or her hand. This player then sees if the selected card makes a pair with their original cards. If so, the pair is discarded face up as well. The player who just took a card then offers his or her hand

to the person to their left and so on. A player is allowed to shuffle his hand before offering it to the player on his left. In some variants, all players discard after the dealer has drawn.

The objective of the game was to take cards while discarding pairs until one is left with no cards. The player left with the Lazy Man (that has no matching card) loses the game.

Açogueiro / Butcher	Gari / Dustman
Agente de Saúde / Health Agent	Médico / Doctor (physician)
Artesão / Artisan	Pedreiro / Bricklayer
Bombeiro / Fire fighter	Policial / Police officer
Carteiro / Milkman	Professora / Teacher
Enfermeira / Nurse	Verdureiro / Greengrocer

Table 4. Occupations in Lazy Man game

To address the most important activity in nutrition, cooking, we developed a series of workshops for the local community. These workshops took place in the ambulatory (Table 5).

How to buy products and read labels	This workshop was based on the following observation that came from the doctors, nutritionist and Health Agents alike. When locals get extra money, women tend to buy pleasurable food stuffs high in calories but low in nutrition. To combat this habit, this workshop taught them to read labels in packages, and took them to groceries to learn to shop better. It also taught domestic budgeting and accounting.
How to have your own garden	Another observation was that as anywhere, Brazilian food culture had become industrial over the last three decades, and few people knew how to grow their own greens even though some parts of Vila Rosario is fertile and climate warm. Since the household budgets tend to be inadequate, this workshop instructed mothers to grow fruits, vegetables, and herbs (both medicinal, aromatic and culinary). They did not need to have a huge space to the kitchen garden, as they could have vertical gardens made of recycled plastic bottles that can be used to make beautiful vertical vegetable and herbs gardens. These gardens could be placed indoors where they served as decorative elements.
How to organize the kitchen	Most families do not have the necessary utensils for preparing and eating meals, which was above all a hygiene risk. One workshop taught how to develop these out of recycled materials. For instance, the workshop taught them to make separate cutting boards for meats, poultry and vegetables.

Table 5. Workshop program built for IVR

Health care web portal and identity program for IVR

Finally, we built a Web portal for health agents and doctors. The portal addressed one of the main problems health agents faced, communication with doctors working in the city. Health agents often faced difficulties in diagnosis and in interpreting the often very ambiguous signals of the treatment, and needed for this reason expert advice. The doctors, however, were able to spend only a limited amount of hours in the ambulatory. Another problem it addressed was inputting the research data for evaluation and medical research.

The identity program we created for IVR gave it a unified, easily recognizable face built from local colors and flowers. With this design, we wanted to make sure people would recognize health agents and treat them seriously as a source of relief. The program consisted of a logo and typeface applied to the Web site (see any of the designs), all graphic designs, as well as a “uniform” for health agents, consisting of a hat, a vest, t-shirt, bag, and some accessories (for t-shirts, see Figure 4).

Testing the design program

When designing for people whose world is as different from the designers as Vila Rosario, we wanted to test our designs carefully with a four-part program to make sure they are free of errors, of professional quality, and understandable down to detail. The testing program consisted of four activities.

Tests in vila rosario

A batch of tests was done in Vila Rosario with Health Agents and some of their patients. Figure 10 is from one test. We organized tests for characters, posters, tuberculosis booklets, nutritional questionnaire, health agents’ uniform, and Vila Rosario Institute’s logo.

Some designs received negative feedback and were dropped from our design program. For example, we dropped a clownish mascot character from our program when we learned that he resembled a local character.

Most of our designs were intelligible to Health Agents. For example, the Health Agent Deolinda wrote:

His appearance is very similar to Dr Claudio Costa Neto. He transmits a desire to transform Vila Rosario. He wants to develop our community and make it better. He transfers lots of energy to all of us.

Some designs were refined. For instance, one of our posters (Figure 11) was about the importance of hygiene and of keeping the hands clean. The tests indicated that the poster is clear: it shows the bacteria and germs and how they get into the hands, tells people to keep their hands clean, and that need soap for proper washing. This poster also reached not only children, but also adults. However, we learned about problems in typography and changed the letters T and P to be more legible.

Figure 11. Example of a test of a hygiene poster

Expert tests

Next we tested our designs with specialists in tropical diseases for their medical and scientific accuracy. (Figure 12).

Figure 12. Testing the designs with doctors

Testing cultural assumptions in windhoek, namibia

The third batch put cultural assumptions to test. The drawback of our reliance of the notion of form of life was that our designs built on Vila Rosario. For this reason, we wanted to test our designs and process in another culture. When we heard about a 2008 workshop in Windhoek, Namibia, we joined it to study how much cultural specificity we had built into our designs (see Miettinen 2007).

We learned that our program as such is robust and works in Namibia, but the symbols need local adaptation. We co-designed our most obviously Brazilian icons and symbols with Namibian designers and nurses. Another thing that needed local adaptation was the disease. The main problem in Namibia was HI, not TB. The thematic universe of poverty, hygiene and nutrition, however, did not change. (Figure 13).

Figures 10 and 13: Figure 10. Participants filling the tests, Figure 13. Tests in Namibia

Streamlining and transferability

Few designers have the luxury of spending more than a year in fieldwork. We had to streamline our process to turn it into a proper social design tool, and the way to do it was to conduct the whole process that took us several years in about two months. An opportunity came to us through doctors in the Vila Rosario network who have been working in Vila Mimosa, Rio de Janeiro's main hub of prostitution and HIV/AIDS. We went to Vila Mimosa in 2010 and created designs to illustrate the transmission mechanism of HIV for the prostitutes, most of whom were illiterate.

Vila Mimosa and Namibia helped us to streamline our method into a process that could be done in two months and that could be adapted to circumstances other than Vila Rosario. Vila Mimosa turned Vila Rosario into a prototype of a community design program (Figure 14).

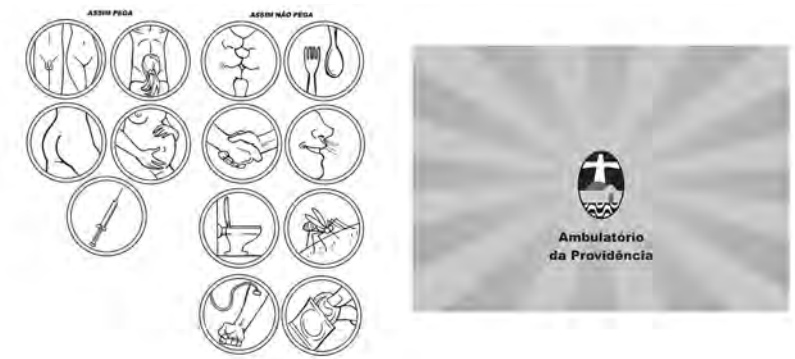

Figure 14. Design details in Vila Mimosa: instructios for protection (left) and the logo of the treatment program

The robustness of the design program

Community design is often done in a one-shot style in which a designer enters a community, organizes a workshop, and leaves after the designs are done. The community is left on its own premises to continue the design program. This approach, we thought, was wrong, and built on a fatal misunderstanding of how communities function. The danger was there, however. Our funding did run out one day, and as we finished our study and moved to Brasilia, we could not keep in touch with health agents on a continuous basis anymore.

To make sure we would not reject health agents, we decided to use new communication technologies. We are still in contact with key persons of the community using electronic tools, especially with the health agents Clara and Joseane. Nowadays Facebook is part of some health agents life, and it was social media that made is possible for us to keep in touch with Clara and Joseana.

Figure 15. Health Agent are still in contact with us through Facebook

Here, the process went beyond our initial theoretical influences in empathic and participatory design. We have kept in touch with the health agents for years after our fieldwork. This has been made possible by new media, and in particular social media. The change has been amazing. When we begun our

fieldwork, most Health Agents were computer and mobile phone illiterate. Today, they are much more fluent users of these communication technologies, and have Facebook pages.

Discussion

This paper has described a design research project conducted in Vila Rosario, Rio de Janeiro. Vila Rosario was an impoverished neighborhood about 20 km north of downtown

Rio de Janeiro, and about 30 km north from the famous beaches of Copacabana and Ipanema. Its main health care issue was tuberculosis and its complications. This disease became our focus of attention: we created a design program that focused on its etiology and treatment, and situated this program in the local community by working with local health agents and doctors who assisted them.

The project started from empathic and participatory design (see Mattelmaki et al. 2014; Ehn 1988), but finally took its form from the Brazilian teacher Paulo Freire and his philosophy best expressed in his classic volume The Pedagogy of the Oppressed. Freire's main focus was on what he called conscientização (conscientization), which he saw a basic condition of changing the living circumstances of poor people in Brazil. What Freire gave us was an approach that told us to go into the local community and study it carefully while still talking to experts. Freire also gave us a stepwise methodology for working with a local community in developing designs for it.

In three respects, however, we went beyond Freire. First, we were worried about our cultural assumptions, and checked these in a workshop in Windhoek, Namibia. Our process worked in Namibia, but we had to redraw some of the symbols. Second, we stremlined the process by replicating our study in Vila Mimosa, Rio de Janeiro's main red light district. This helped us to turn our years-long process into a two-month process that could be applied anywhere in Brazil. Third, we used social networks in keeping in touch with the local community. This helped us to stay in touch and to help the locals in their design problems.

Seen from a larger perspective, the Freirean process took us to a direction quite different from current approaches in community design. Our work was certainly not technocratic, legislating change to the community. It was not agonistic either in that we avoided using antagonizing artistic statements as a way to conscientização (see Markussen 2011; DiSalvo 2012). Rather, our work was close to community organizing in the social sciences, and in some fields of participative art (Kester 2013). The closest analogies came, in fact, from Brazilian social design (Couto and Ribeiro 2002; Cunha 2005), which stresses cooperation rather than agonism as a starting point for community design. The approach has many affinities with consensus-oriented design (Winschiers-Theophilus et al. 2012), which has emerged a few years after our study.

Another aspect we learned was the importance of social media, which saw daylight during our study. Based on our experience in Vila Rosário, we can suggests that this long term

contact should be a part of empathic and participatory design for two reasons. First, social media makes it possible for anyone in design to keep contact with people long after the actual design phase. Second, keeping in touch does not require massive amounts of work or other resources in today's networked world.

In some ways we learned in the process that old principles in working with communities still work best. To propose change in a community, it is necessary to understand it well. It is also important to work with its social organizations rather than assume an expert position. Finally, we must identify the key stakeholders to win their respect. Without them, there is no future to community design. We also learned a few things we believe are new. We were able to build a robust process by building on Freire and philosophers like early Lukacs, early Sartre and Marx in his back. However, we did not need to make expert or avant-garde assumptions to make our design program work. The basic beliefs of empathic design worked well in reminding us to stay partners and interpreters rather than act as legislators who know better.

During our research and after the process our status was changed by the context. We arrived in the community as experts that would develop a portal to improve the community. During our fieldwork we became apprentices, who wanted to learn about Vila Rosario. Over the years, we became friends and pro bono design consultants for the community.

Our final comment is about our ethics, which we shared with world design (Miettinen 2007; Winschiers-Theophilus et al. 2012). Design as usual is a privileged, first-world activity. One of our key principles in designing the world was that it is exactly poor people like those living in Vila Rosario who deserve good design. We think we achieved this aim; at the end of our fieldwork, one of the health agents told us that our work said to the health agents: "You are important!"

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