DESIGN FOR HOPE

Designing Health Information in Vila Rosário

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Objectives and Questions

Brazil is a country of contrasts, with huge cultural diversity. Its population was 190,732,694 in November 2010, according to IBGE – Brazilian Institute of Geography and Statistics, and it can be seen as a developing country, while at the same time it has many elements that could raise it into the developed world. The country's community is proud to be recognized as successful football players, and also as Latin America's economic leader, with its wealth based on its vast natural resources and its large labor pool. Although the country is amongst the richest in the world in natural resources and even in Gross Domestic Product (GDP), a huge gap of income exists between the richest and the poorest. About one in four Brazilians lives below the

international poverty line and cannot afford to buy enough food. Despite the recent improvements on family income, 25.6% of families are considered at risk of poverty or social exclusion (IBGE). As a result of these inequalities some chronic diseases have been making their way mainly amongst the poorest layer of the population. One of these diseases is tuberculosis, which in some areas of Rio de Janeiro State rates amongst the highest in the world. There are other problems as well.

A high level of incidence of tuberculosis amongst inhabitants of any society is suggestive of misery pockets existing in that society. The active search for new cases of tuberculosis may then be used as a probe to reach individuals living in this state of misery. Once the cases of misery are diagnosed, how could these persons be brought back to citizenship? How could these persons be re-integrated[1] to the mainstream society?

THE VILA ROSÁRIO INSTITUTE PROGRAM

This study was done in Vila Rosário, a community located in the municipality of Duque de Caxias in the state of Rio de Janeiro, Brazil. I will describe Vila Rosário in detail later in this book, but a brief outline helps the reader here. Vila Rosário has approximately 60,000 inhabitants, most of them with a very low socio-economic status; a low educational level; a high level of tuberculosis and other tropical diseases; inadequate housing and other problems, such as addiction to alcohol and drugs, and malnutrition. The many labels for these communities include "minority groups" and "marginalized communities." They are seen as people who do not have skills, abilities, needs, or expectations and, because of this, are poor. Facing this

1 In our research we are using the term inclusion as a process and integration as a state.

stereotyped and, as a consequence, distorted vision, they become "invisible" for most of our "developed" communities, who prefer to ignore them or treat them as people who need charity. Moreover, these invisible communities have little (or no) access to new information technology, such as mobile phones, computers, and the internet. This is a huge community with important problems, like the lack of education, insufficient incomes, limited access to health care, and so on. Problems that can be alleviated by suitable design solutions.

The work of the Institute Vila Rosário (IVR) is trying to change this panorama. It grouped scientists with different backgrounds from Rio de Janeiro universities and research foundations, to propose intervention in the small community of Vila Rosário, an area only ten miles from downtown Rio de Janeiro, using techniques and ideas derived from science and technology. The program associated these pockets of misery to a group of causes observed among these people. These causes are linked in what they call "The Chain of Misery." This chain is made of five main links: disease, hunger, low or no income, lack of education, and inadequate culture. For example, there is disease (tuberculosis) because there is hunger. There is hunger because there is not enough income to buy food. There is no income as there is not the necessary education to get a job that could sustain a family. And, there is no education because the culture is inadequate to reach any level of education.

The method used by the IVR group is based on cooperating with people who live in the area. For this purpose, some inhabitants of the area were employed as community health workers. Besides, they formed an association with the Catholic Church, which has decades of experience with people living in the area, and also a partnership with the health services of the municipality. Currently the results achieved are measured by the

number of cured patients, and the improvement in income and self-esteem observed amongst the inhabitants of the area.

Faced with this situation, a stakeholder of Vila Rosário Institute came to Helsinki in November 2004 and proposed a research project to me, Marcelo Ortega Judice and our advisor Ilpo Koskinen. The brief as given to us was to develop health information systems to improve the community members' lives.

The term "information system" has in this dissertation the following meanings. Information systems are social systems whose behavior is heavily influenced by the goals, values and beliefs of individuals and groups, as well as the performance of the technology. Social structure underlying human interaction may be seen to underlie important social systems including the economic system, legal system, political system, cultural system, and many others. For example, family, religion, law, economy and class are all social structures. The social system is the parent system of those various systems that are embedded in the social system. Information system is the arrangement of people, data, processes, presentation of data, and information technology that supports our everyday needs. Information system consists of the network of all communication channels used within an organization.

Before going any further, I have to stress that research and design leading to this thesis was done together with my husband Marcelo Judice, who reports the Vila Rosário case from another perspective in his thesis *You Are Important!* (M. Judice 2014). There is some overlap in my thesis and his, but the theses have a different focus. My thesis focuses more on the research process, and it builds on Paulo Freire's thinking. His thesis focuses more on actual design work, and builds on the notion of language games. We have tried to avoid repetition as much as we can, but some repetition, obviously, has been unavoidable.

SOCIAL DESIGN IN BRAZIL

The first literature I consulted in my study was social design literature from Brazil. The inauguration of Escola Superior de Desenho Industrial (ESDI), the College of Higher Education in Industrial Design, in the beginning of the 1960s started a tradition of design associated to industry. According to Niemeyer (2000), the beginning of the industrial design course in the State of Guanabara had the support of the Governor, whose

TABLE 1.1 EXAMPLES OF SOCIAL DESIGN PROJECTS IN BRAZIL		
	At São Paulo State University – UNESP, the Laboratório de Design Solidário – Labsol (Laboratory of Solidary Design –faac.unesp.br/#47,879), which works with communities and groups that have their financial base grounded in craft.	The State University of Maringá (UEM) has a multicampus policy. It maintains a regional campus with the objective of contributing to economic development and improvement of human development indicators in its home region. Its mission reflects the role of its mother university with the local community in regional development, as well as on the integration of academic analysis and solution of social problems. A good example of an inclusive design project is Sleepwear for Elderly Women - Idosas Institucionalizadas e o Vestuário Sleepwear: Requisitos Projetuais e Design Inclusivo. Rumos da pesquisa no design contemporâneo: inserção social (Menegucci et al. 2013).

government focused on innovation and pushed industrialization. The Industrial Design course from ESDI “emerged as the institutional space that would produce the national identity of the Brazilian products” (Niemeyer 2000). ESDI curriculum was shaped in part by the German School of Ulm. Maybe because of this influence, the Brazilian Modernist aesthetic was pushed aside the rationalist aesthetic of Ulm, which disregarded the reality of the Brazilian industry (Niemeyer, 2000).

The Graduate Program in Design (PPGDg) of the Federal University of Maranhão (UFMA) has the implementation of Social Design as one of its objectives, seeking the welfare and quality of life of the local and national population – described on the paper from Diniz et al. (2013).

As Margolin (2002) describes, the city of Curitiba, Brasil, is an important case in which design thinking is a base for many forms of civil action, and quality of life. Starting with eco-minded mayor architect Jaime Lerner, Curitiba was on the international map.

In Rio de Janeiro I had the opportunity to see The Coopa-Roca project - Crafts and Sewing Cooperative of Rocinha in Rio de Janeiro (Coopa-Roca - coopa-roca.org.br/default.asp). Its objective is to train, coordinate and manage the work of women from Rocinha, Rio’s world-famous favela, and develop handicrafts focused on the fashion and design market.

There remains a tradition to educate students who focus on light and heavy industry, but several designers and design schools are also involved in social design or "partnership design," as it is sometimes called. In Brazil, social design projects are increasing, not only done by universities but also by marketing departments. In 2013, I had the opportunity to take part on the IV Simpósio de Pesquisa e Pós-Graduação em Design at São Paulo State University – UNESP, in which I had contact with many designers with experience in social design. Table 1.1 describes some examples.

These projects, however valuable, were a disappointment to my purposes. They were design and education projects, rather than well-documented research. It was difficult to find literature about these projects, and in particular I did not find literature evaluating the results of the projects. To get a better idea of the Brazilian approach to social design, I had to zoom into one school and its approach. Pontifical Catholic University of Rio de Janeiro (PUC-Rio) is one of the best Brazilian examples of a university as an important place for social design development, and can serve to highlight how "partnership design framework" can operate in design education.

From 1982, partnership design activities began at PUC–Rio, meaning that the students were brought to the real context of the intervention and dealt with real users, their needs and wishes. Formerly and traditionally, students would have been required to imagine the users and the contexts, and as a consequence they would have created a mental image of the social interaction they believed could be real. Based on this imagined scenario the students would have generated their products and tested them in the classroom with other design students (Couto & Ribeiro, 2002). This model of education based on abstraction and imagination of the real context, with no contact with the real

users, generated projects and products lacking social meaning, and most of these failed.

This leads to a question of how to define design and design activity. Couto & Ribeiro (2002) pay special attention to this. Numerous definitions from many other authors such as Gui Bonsiepe (1978), Christopher Jones (1976), and Papanek (1971) motivate the authors of this paper to propose design as a process of social interaction. According to the authors:

> Design is not socially neutral. Design is an activity that influences and is influenced by the balancing of interests among different social groups that participate in its process and deal with objects or systems. (Couto and Ribeiro 2002)

Two important authors that helped to define Design and Design Activities in this research were Bello (2008) and Valtonen (2007). Bello framed the problems of Design definition, while Valtonen highlighted the different roles for designers and statements on design.

According to Ripper (1990, quoted in Couto & Ribeiro, 2002), one of the pioneers of partnership design at PUC-Rio, the difference between partnership design and design for industry is based on a productive design model for industry, where users are not involved in the product development process. Product design for industry has traditionally involved such short timeframes that the real user has not been taken into consideration in an adequate way. Instead, any "user approach" has been relegated to sophisticated marketing techniques, which do not always consider the socio-economic or technological context.

In contrast, the main goal of "partnership design" is to develop projects that include the users in almost every stage of the design process. With this approach, partnership design claims to change the users' situation from a marginalized

population to a participative population that can express its needs and desires.

I had the opportunity and privilege to have Rita Couto as a teacher, whom significantly reinforced the framework of social design. During this time Couto stressed that social design has limits, and when we work in this field we have to understand: who our populations are and what their real needs are; the differences between what the populations need and what they want; and how to evoke their emotions to understand their dreams. When conducting social design interventions we must attempt to gain a deeper understanding of social needs, and to build the necessary background for this understanding. We also need to have the skills to share someone else's experiences by imagining what it would be like to be in their situation or by doing what they do. And finally we need to have a holistic approach, a view to the whole scope involved in the situation.

Couto always highlighted the importance of building a strong background in anthropology, psychology, sociology, public policies, among others. She also emphasized the importance of working in interdisciplinary groups for more effective result.

Social designers are thus people doing projects, interventions and research to find ways to influence people (communities, public and private sectors, among others) to understand it is possible to extend the opportunities available in our so-called "developed" society to those who are often hidden from society. The social design approach is an ethical approach, based on human rights, focusing on the principles of equality and respect of individuals' qualities.

The social design study programme at PUC-Rio aims to stimulate the students' capacity to reflect, to ground design work on a solid theoretical base, and to promote practical

exercise in context. The students are oriented to deal with problems of their reality. The teachers believe that the approach in a real context contributes not only to stimulating creativity and developing a critical sense, but also helps the students to discover values of its own culture. Social design provokes a practical interaction among different areas of productive knowledge and interaction between the university and the diverse segments of the society.

DESIGN FOR SOCIAL CHANGES: WORLD DESIGN

When I was doing my doctoral studies in Helsinki, Marcelo and I had the opportunity to work with the World Design Research Group. For example, we partook in the workshop *Design Your Action,* which was organized in conjunction with *Connecting: Conference on Design History and Design Studies,* and also in a workshop run by Sylvia and Victor Margolin, organized by Paula Bello, then our fellow doctoral student.

According to Miettinen (2007b), the World Design Research Group was a cross-disciplinary group active in producing seminars, exhibitions, workshops, and publications. Its mission was to develop design outside the market, with an eye on designing for countries outside Europe and North America. It had been working since the beginning of the Millennium. Taking part in the World Design Research Group was a possibility to exchange information and promote very rich discussions. So far, the group has produced seven PhD theses and several other publications. Its work has mostly focused on Africa, but some studies have also been done in Asia and Latin America. The group focused on craft and always used contextual methods: its researchers worked with people in developing countries for long

periods of time. Also, they consistently tried to create business models that would guarantee the future of the projects after the funding ran out.[2]

Following Miettinen (2006), social design intends to contribute to local economic development and aims to improve human well-being. Social design used to be seen in a stereotypical way as voluntary work, and many times it is seen with the idea of charity, aid, and the like (Miettinen, 2006). As Margolin & Margolin (2002) state, a social design project's main aim is to satisfy the needs of underserved or marginalized populations.

Social design's target groups are thus marginalized communities that are not usually regarded as potential consumers by companies and industries. The marketing sector still resists seeing social design as a niche, at least in Brazil. Ripper (1990, in Couto & Ribeiro, 2002) tells that social designers seldom concentrate on technical aspects at the beginning of the project, a characteristic that can often provoke a misunderstanding about their competence. This does not mean these professionals are about to ignore any requirements related to industrial production. Social designers are prepared and have the skills to meet industry demands and specifications. The difficulty lies in identifying a producer or investor that has interest in producing it (Ripper, 1990, in Couto & Ribeiro, 2002).

As this situation is bound to change, social design will begin to make good business sense. This commercial argument can be based on the fact, for example, that the population is ageing, and this situation will bring about profound and permanent changes to the marketplace.

During a workshop at the University of Art and Design Helsinki, Sylvia Margolin highlighted how design can deal with aging. The baby boom generation is the fastest growing population segment worldwide, and its demands must be acknowledged with

open minds in order to foresee new opportunities for innovation. She described a good example of a project for aged people called AgeLab[3], in which this particular part of the aging population is addressed, to invent a future for healthy and active living. These changes in the marketplace reinforce Margolin & Margolin's (2002) idea that design for markets and design for society have to be seen "as two poles of a continuum."

As Ripper (1990, in Couto & Ribeiro, 2002) had stressed a bit earlier, in facing this industry or market reality, social designers will undoubtedly find at universities their space to work, par excellence. Conducting research and being teachers in an academic environment can allow the researcher to manage the project according to the relevant contingencies, without time pressure or technical requirements as the main gears of the project. In the authors' opinion, design schools are the appropriate place for redefining boundaries and developing the social design arena. As Margolin & Margolin (2002) suggest, "more attention has to be given to changes in the design education of designers that might prepare them to design for populations that are in need rather than for the market alone."

OBJECTIVES AND QUESTIONS

This study has two objectives. First, it aims to produce empirical results that make designers of information systems for vulnerable communities, more prepared to meet the real

2
Theses focusing on Africa include Miettinen (2007a), Kabiito (2010) and Huhtamaa (2010). Nugraha (2012) studied Indonesia and Sorainen (2006) Kalpourkan in Iran. Bello's (2010) work was done in Mexico. For Miettinen and Huhtamaa, the business model built on tourism; for Nughara and Bello, on SMEs; for Sorainen, on museums and local markets. Kabiito focused on art practice rather than design.

3
http://agelab.mit.edu

needs of communities members. Second, it aims to analyze and describe the application and the implication of empathic design as well as Scandinavian participatory design and ethnographic methods in Vila Rosário. These inspirations are explained below in more detail.

These objectives translate to a series of more specific objectives. Initially, the aim of the study was to create a health care portal for Vila Rosário. The aims were to identify contents through a user-centered process; to create a structure for these contents (which things are up, easily accessible etc., which are down; search functions etc.); and to develop an Interface suitable to people involved at Vila Rosário project. The overall aim was to prepare people from Vila Rosário to use e-government by creating a process of digital inclusion at Vila Rosário.

As research went on, however, the aims changed from hi-tech to lo-tech. Instead of relying on information technology, we decided to supplement the portal with lo-tech information distribution system. Our objective became creating low-cost, suitable designs to Vila Rosário context (communal bulletin boards, diaries, posters...) and finding a way to best distribute that information.

The reasons for this change happened as our study progressed from stereotypes into more structured observations in Vila Rosário. Most notably, Vila Rosário has a high illiteracy rate. Relying on information and communication alone, we reasoned, would lead to digital exclusion rather than inclusion, and would work against our aims. Also, there were problems with infrastructure that made many developed world design solutions and technologies unviable. One of these problems was unreliable electricity, and another was local distrust on many local authorities like the police force. Simply, many issues Europeans can take for granted in building their designs were not there.

Finally, empathic design and participatory design suggested an alternative, building designs on things people understand and can relate to. As our initial hypothesis about information systems increasingly failed under the pressure of data we were exposed to, an alternative hypothesis suggested by our Nordic theoretical inspirations became increasingly more attractive. We respecified our problem and decided to build on a mixture of high-tech and lo-tech designs rather than only rely on electronics.

After the respecification, our final research questions came to reflect the development of aims. The main question of this book is: how to develop information systems for Vila Rosário's Community that could be cost-effective in social and economic terms? Another main question is how to integrate the users' social and cultural contexts into the designs? As this is a design study, we furthermore ask a series of four design questions. The first design question is what kinds of information systems are going to be useful and enjoyable for the residents of Vila Rosário? The second question is how to create information systems suitable for this context? Third, we ask how to distribute health-related information into this poor community with little access to computers, Internet, and mobile phones. The final question is how to make those information systems effective, through empathic and participatory design?

2

Designing for Hope

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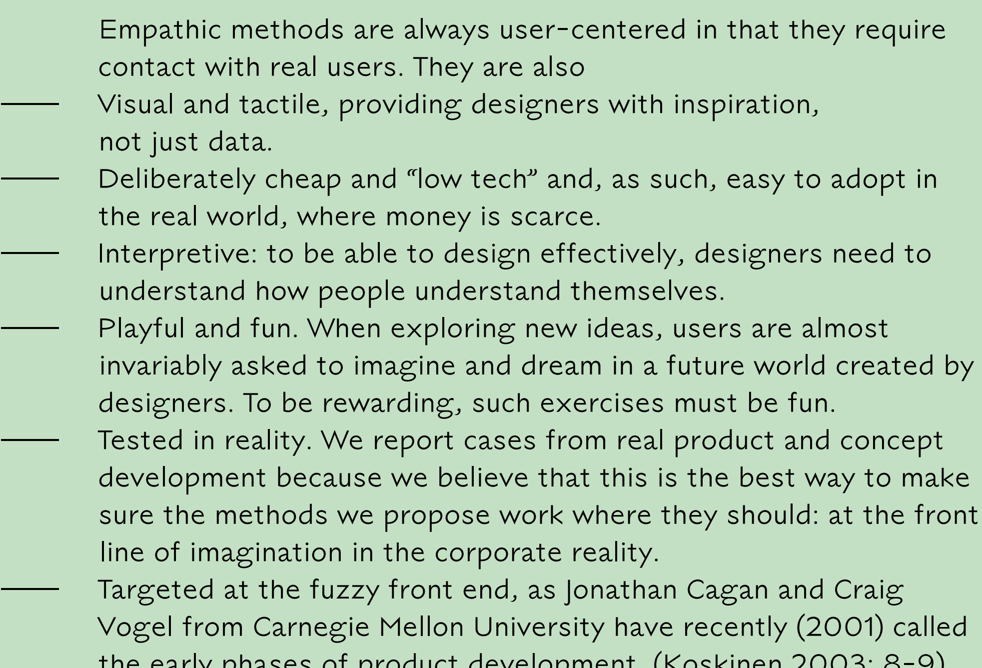
The Long Tail of Trust

The roots of this book are in empathic design as it is practiced at former University of Art and Design in Helsinki. Mattelmäki and her colleagues have recently described how research has developed since the end of the nineties, when briefs coming from industry increasingly became less technical and focused on issues like emotions and user experience. In response, design researchers in Helsinki turned to writers like Leonard and Rayport (1997), Patrick Jordan (2000), Liz Sanders (1999), Dandavate (1996), Jane Fulton Suri (1993) and Alison Black (1998), who had written about empathy as a key tool for understanding user experience for design. From these sources, researchers in Helsinki built an interpretive design approach, in which it

was important to study how people make sense of emotions, talk about them, and share to understand situations into which design was to be targeted. Empathic design was part of a larger movement toward context-sensitive design in the nineties, but it was built on design competencies; it shared neither the theory nor the politics of movements like participatory design and activity theory (Mattelmäki et al. 2014).

Theoretically, the roots of the program are in Herbert Blumer's symbolic interactionism, though there have been more than a few hints from ethnomethodology (see Kurvinen 2007; Lee 2012). To do design properly, designers need to study those meanings people act on, build together, and change together.

More important than theory was, however, a conviction that design research must be done in real life with methods that are visual and tactile, inspiration-enhancing, deliberately cheap and lo-tech, playful, tested in reality, and targeted at the fuzzy front end of the design process. As Koskinen writes, empathic design has consistently followed a few principles:



> Empathic methods are always user-centered in that they require contact with real users. They are also
>
> — Visual and tactile, providing designers with inspiration, not just data.
> — Deliberately cheap and "low tech" and, as such, easy to adopt in the real world, where money is scarce.
> — Interpretive: to be able to design effectively, designers need to understand how people understand themselves.
> — Playful and fun. When exploring new ideas, users are almost invariably asked to imagine and dream in a future world created by designers. To be rewarding, such exercises must be fun.
> — Tested in reality. We report cases from real product and concept development because we believe that this is the best way to make sure the methods we propose work where they should: at the front line of imagination in the corporate reality.
> — Targeted at the fuzzy front end, as Jonathan Cagan and Craig Vogel from Carnegie Mellon University have recently (2001) called the early phases of product development. (Koskinen 2003: 8-9).

FIGURES 2.1-2.2
Analyzing data together in Brazil.
Psychologists, Designers and Doctors.

In analyzing the returns from these studies, design researchers seek to explicate meanings for design rather than to explain these meanings (see Koskinen et al. 2003: Chapter 3). This typically happens in workshops with several kinds of experts, as Figures 2.1–2.2 show.

This research program first focused on interpreting emotions and experiences for design, but by 2005 the main focus had become co-design: how to introduce empathy into networks and organizations that do design. After 2008, the main focus has been how to make empathy more imaginative to respond to the calls for radical innovation (Verganti 2009). So far, the research program has produced hundreds of articles and papers in conferences, several monographs, and more than ten PhD theses. Its influence has been global (see Mattelmäki et al. 2014).

The problem with empathic design when I started my study in 2005 was, however, that it mostly dealt with products and specifically, electronic products. In Vila Rosário, we were dealing with ordinary people who had many problems in their lives, and our designs had to address these problems. Although empathic design gave us an appreciation of emotions and experiences, and many inventive methods, I had to shift the attention away from products to communities.

PAULO FREIRE AND PARTICIPATORY DESIGN

Another inspiration for this study came from a classic text of participatory design, Pelle Ehn's "Work-oriented design of computer artifacts" (Ehn 1988a). Ehn's text describes in detail how participatory design built on Marxism and Ludwig Wittgenstein's philosophy, but also, and more importantly to me, on Freire. As Ehn notes, the research approach he built in the seventies was action research with trade unions. The approach had two main sources: the computer scientist Kristen Nygaard's work with the Norwegian Metal Workers' Union and Paulo Freire's Pedagogy of the Oppressed (Ehn 1988a: 8-9).

> After a few years of practice as a computer programmer and systems designer I started as a PhD student at the Department of Information Processing at the University of Stockholm. This was in the early seventies, a politically turbulent period in society in general, as well as at the universities. Influenced by this political 'climate', and by my limited practical experience my field of interest was systems design and democratization... Two years later I summarized my new understanding in *Bidrag till ett kritiskt socialt perspektiv på utvecklingen av datorbaserade informationssystem (A Contribution to a Critical Social Perspective on the Development of Computer-based Information Systems),* whose truly academic title stressed its scientific claims. I proposed an interdisciplinary perspective for research into systems design and democratization. The research approach I advocated was action research together with trade unions, and here I was strongly influenced by Paulo Freire and his 'pedagogy of the oppressed' as well as by Kristen Nygaard and the work he was doing together with the Norwegian Metal Workers' Union.
> (Ehn 1988a: 8-9, the latter italics added).

The key concept Ehn learned from Freire was conscientization – making people conscious of their situation in order to make them change it, either being oppressors or oppressed. As Ehn notes, the method was a great source of inspiration in classic participatory design projects, but also in an emerging

Scandinavian design research approach that brought together trade unions, computer scientists and social scientists to design better computer artifacts (Ehn 1988a: 93-94). This research approach came later to be known as "participatory design." Its method was strongly influenced by Freire.

> Though developed for the situation of poor Brazilian peasants, [Freire's] method was in the mid-seventies a great source of inspiration for us in the DEMOS project and in general for the emerging research cooperation in Scandinavia between trade unions and computer and social scientists on design and use of computer artifacts. The method is based on 'students' and 'teachers' forming investigating groups. The teacher, researcher, designer etc. share everyday life with the members of the group for some time. From what they see and understand they help formulate generative themes i.e. a complex of questions that can be useful in the groups' reflection over their own understanding of their situation... The dialogue between e.g. workers and designers is based on these generative themes, and in the breakdown process that follows they learn from each other, and participate jointly in the integrated process of change... These questions may be formulated in terms of a discussion of a computer based planning and control system that management has announced will be introduced. But they will also be based on theoretical knowledge of managerial strategies, division of labor, technological development, power structures, trade union resources, etc. (Ehn 1988a: 93-94).

What Ehn and emerging participatory design got from Freire, then, was a complex of ideas stressing the need for building a dialogue on everyday problems that bother people and alienate them by blocking their access to decisions that shape their futures (Ehn 1988a: 283). In another paper, Ehn has described how the design approach of UTOPIA improved dramatically when the team "started to understand traditional tools as a design ideal for computer artifacts - the design of tools for skilled work"; it started to make "joint visits (designers and graphic workers together) to interesting plants (and discussed with

users there), trade shows, vendors etc."; it started to dedicate "considerable time for learning from each other: designers about graphic work, and graphic workers about design"; and finally, it started to "use design-by-doing methods and descriptions in the language of graphic work, i.e. mock-ups, work organization games etc." (Ehn, 1988b: 145).

What participatory design and Freire taught to me was that empathic design is not enough in changing invisible communities with complex social and economic problems. In these communities, it is important to study the root causes of these problems, and find ways to communicate not only the problems and their consequences to people, but also find ways to make them conscious of the problems so that they can start to overcome them.

While the overall approach of this book comes from empathic design and Ehn, there are other things, however, that cannot be learned from these sources when we take participatory design back to Freire's home in Brazil. In particular, participatory design makes several assumptions about the people studied. When we design for poor areas in Rio de Janeiro, many things Ehn and his followers could take for granted are not there. These include technology and organization, but also more elementary issues like literacy. Furthermore, Ehn and other focused on work, which is not the case in this book, which focuses on health in a poor area. The concern of this book is how people live in Vila Rosário, not how they can better gain control over their fate at the workplace.

DESIGNING FOR AUTONOMY

How to design for the oppressed? How should we do design for oppressed people? Freire has two answers that help us to specify Couto's social design approach further.

DESIGNING FOR HOPE

The first answer is methodical. If we build design on Freire's pedagogy of the oppressed, the first thing is to make people from the community trust you and believe in your work. They only open up their lives for researchers if they trust them. They need to understand the objectives of the research, and that the research outcomes will develop their community and their own lives. The researchers need to understand that answers to their questions do not come often from the people's words; answers may lie in their gestures, in their silence, in their "not knowing". Designers need to empathize and not only be sympathetic with the community situation. As Freire writes in his Pedagogy of the Oppressed, his book presents what he has termed

> the pedagogy of 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)

For Freire, his methodology requires that designers and the people are co-investigators; people are not objects of investigation (Freire 2005: 106).

When we take a methodical look at Freire's pedagogy, we find a process roughly analogous to field research in social sciences, but also in empathic design. For Freire, the process of investigation aims at uncovering the people's "thematic universe," which means making sense of the complex Freire calls people's "generative themes." It is this analysis that inaugurates the dialogue of education as the practice of freedom, as Freire notes (Freire 2005: 95-96).

The process of analysis of these themes proceeds in four stages. In the first stage, (here) designers select an area in

which they work, study secondary sources, and then recruit local people to assist them in their investigation. They also start to do their own fieldwork in the area, listening to people and observing their activities. This research is done in teams.

> Once the investigators have determined the area in which they will work, and have acquired a preliminary acquaintance with the area through secondary sources, they initiate the first stage of the investigation... In this first contact, the investigators need to get a significant number of persons to agree to an informal meeting during which they can talk about the objectives of their presence in the area... If the participants agree both to the investigation and to the subsequent process, the investigators should call for volunteers among the participants to serve as assistants... Meanwhile, the investigators begin their own visits to the area, never forcing themselves, but acting as sympathetic observers with an attitude of understanding towards what they see... Visit upon visit [the investigators] attempt to "split" it by analyzing the partial dimensions which impress them... After each observation visit, the investigator should draw up a brief report to be discussed by the entire team, in order to evaluate the preliminary findings of both the professional investigators and the local assistants (Freire 2005: 110-113).

After the preliminary phase, researchers enter the second stage by selecting a few problems and grouping them into categories they use in thematic investigation. As Freire notes, these codifications must "represent situations familiar to the individuals whose thematic is being examined, so that they can easily recognize the situations (and thus their own relation to them)." These codifications should form a "thematic fan" that stimulates people to think about their past ways of thinking and knowing, and that stimulates new perceptions and the development of new knowledge. (Freire 2005: 114-115). After studying the whole thematic fan, researchers enter the third stage of the investigation. Designers and other investigators return to the area to discuss their findings with people and also scan these with a psychologist and a sociologist, who are to

observe reactions during these meetings, be these significant or apparently insignificant (Freire 2005: 117). Once this process is over, the last stage of the investigation can begin. This stage is interdisciplinary. Each specialist presents a "breakdown" of his theme and gives a general view of the theme by identifying learning units and establishing its sequence. Other participants to these meetings also have the right to include themes not previously suggested, as Freire notes (2005: 119-120).

When working with invisible communities, is important to analyze observations in teams all through the project with as much people as possible. People need to trust the researchers and the research needs to be committed to the project. Doing analysis together, or at least checking key observations carefully with people, is a fundamental condition for properly understanding the reality that designers are designing for.

In Freire's thinking, the investigation stage prepares design. This is a process of choosing the best channel of communication for each theme and its representation. The means for communication can be visual (pictorial or graphic), tactile, or auditory. It can also utilize many channels. For Freire, the selection of the pictorial or graphic channel depends

> on the material to be codified, but also on whether or not the individuals with whom one wishes to communicate are literate. After the thematic has been codified, the didactic material (photographs, slides, film strips, posters, reading texts, and so forth) is prepared. The team may propose some themes or aspects of some themes to outside specialists as topics for recorded interviews... With all the didactic material prepared, to which should be added small introductory manuals, the team of educators is ready to represent to the people their own thematics, in systematized and amplified form. The thematics which have come from the people return to them — not as contents to be deposited, but as problems to be solved. (Freire 2005: 123).

For Paulo Freire, then, educating yourself is to drench in sense your day-by-day acts. It is important to consider what really contributes to understanding and changing the context you are working with. The important is to learn how to think that reality in the context, with people from the community. It is important to respect and conserve the people's identity. What we do as a researcher needs to be part of the individuals and the community's live. Our projects need to have outcomes that give people autonomy to "stand on its own and walk with their own legs" – making people autonomous. Freire insisted that pedagogy must aim at autonomy. It is a precondition for solidarity, which is necessary for improving the life conditions of people, and also survival. One important point of the pedagogy is that the outcomes need to be given to the community. Designers must give feedback, must implement the projects (products and services) and support the community doing the impact evaluation of their work (short term and long terms).

DESIGN FOR HOPE

Freire's second answer to the question of how to design for invisible communities builds on his humanism. Freire has not only created a method. Rather, he developed a theory of knowledge built from a vision of world based on humanism. In his perspective, when working/developing a research on a context, people should ask how to learn about that context: why you need to learn/understand that context; for what reason you need to learn about that context. And as a researcher you also need to answer this question to your target group. You need also to involve your target group on your research.

This is a thoroughly participatory and democratic understanding of design. For Freire, to awaken people and make them believe that change is possible, it is necessary to know their

context, to experience people's lives. Unless a designer deeply understands their words, their practices, their experiences, their "world", he functions as yet another oppressor. The point is that the experiences people have in the community shape the community in many ways. They shape how they think and express themselves. Their expressions build on their context, on their reality. Designers need to know this reality, not just listen to what people say.

Thus, for designers, it is mandatory to find out what people from the community already know about their own context before they can start finding ways to conscientization, a process of making people better aware of their reality, and help them to believe in their knowledge. The right starting point to a project is studying what people already know:

> 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)

By looking deeper at the situation into its base in reality, a designer can learn from the community and become a co-investigator who can deepen the community's knowledge, by building a project that instigates curiosity and helps them to discover new ways of thinking about their "thematic universe". This, in turn, may lead to engagement and to commitment to the design project.

Following Freire's democratic rationale, it is important to share the dialogue, share the world with others. People share their knowledge and their thoughts, and they build their reality together with other people. Fundamentally, Design for Hope helps people to know their reality by sharing their life histories,

their knowledge, and understanding their ways of interpreting reality. Also, Design for Hope changes the designer by allowing them to change the designer's values, ideas, attitudes, and behaviors, by introducing them to the families, social groups, schools and so forth, which maintain the realities that shape the community's fate.

For Freire, 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. To have this "reading" before going to the field enables a research dialogue with an invisible community. It prepares the community to research; it prepares the researcher to encounter the community; it prepares both parties to understand each others' premises. As he writes,

> 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 spectres haunt the new structure emerging from the revolutionary transformation. (Freire 2005: 54-55)

When following Freire, designers need to see the actions they develop in the community as important, not only because of the answers they get from interviews or from drawings. Much more important is their very action on context itself: it is a process that transforms that context. 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 have thought or talked about.

THE LONG TAIL OF TRUST

In one respect, our study clearly went beyond empathic design, participatory design, and even Freire. After gaining the trust of the Health Agents and working with them to create designs, we did not leave them after our project was finished and our funding ran out. We are still in contact with key persons of the community, using electronic tools – especially with Community Health Agents Clara and Joseane. We built a long tail of trust into our approach. Trust and even friendship are essential in this relationship. New tools make it possible. Nowadays the "the virtual world" is part of some Community Health Agents' lives, and it was social media in particular that made this long tail of trust possible for us.

Thus, unlike most designers, we kept in contact with VR even after finishing the study. It is still nice to wake up with a "good morning" message from Joseane on Facebook. Nowadays I am living in Brasilia, but the distance is not an obstacle anymore, thanks to the way in which Community Health Agents appropriated social media. In terms of my research, keeping in touch has helped me to understand in a deeper way the impact of our project on their lives. Also as researchers, we can still serve the community as volunteers/consultants if they need our help in their work. Over the years, our role first evolved from expert designers into apprentices who wanted to learn from Health

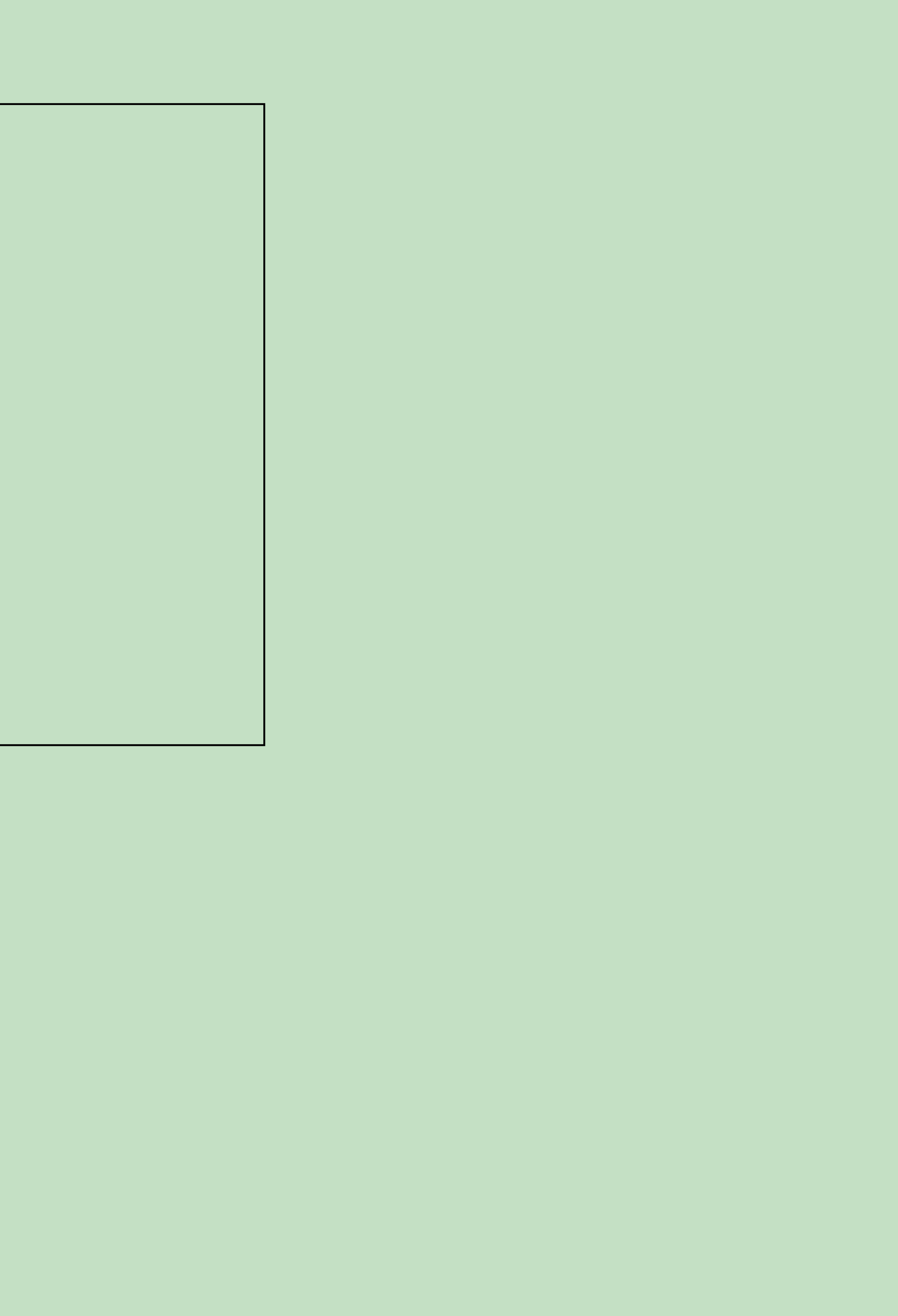
TABLE 2.1 DESIGN FOR THE OPPRESSED INSPIRED BY FREIRE	Search and analyse secondary data; Go to the community, recruit locals to assist in design, and get immersed in data; Identify themes key to understanding the community and its problems; Iterate and return to the community until the understanding is robust enough to be accepted by the community; Create didactic materials with instructions and study these with the local community;

Agents, then into co-designers who worked with them, and finally to friends, volunteers and consultants, who are available with one click (see also Winschiers-Theophilus et al. 2012).

Based on our experience in Vila Rosário, we can suggest that this long term contact should be a part of empathic and participatory design from now on, for two main 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.

3

Probes: Pre-understanding Vila Rosário



The study begun when Marcelo and I were doing our doctoral studies in Helsinki, Finland. Even though we are from Brazil, we were middle-class students, who knew little about life in poor communities like Vila Rosário. Our study started with literature (especially Costa Neto 2002) and other secondary sources like government and state statistics, but we also wanted to get a richer understanding of life in Vila Rosário before doing actual fieldwork. We decided to conduct an initial study with cultural probes, a design research method we had learned from Tuuli Mattelmäki in Helsinki (Mattelmäki 2006; Gaver et al. 1999; Wensveen 2005).

If we look for the meaning of "probe" in the dictionary, we are going to find this definition:

> Probe: "to try to discover information that other people do not want you to know, by asking questions in an indirect careful way"; "to examine something with a tool, especially in order to find something that is hidden" (Cambridge Advanced Leaner's Dictionary).

This is a very interesting beginning in understanding why we decided to use probes, and why we chose probes as an important tool for our design process. We are working with a hidden community, in which some of their members are ashamed of their situation, or feel stigmatized because of their condition. Most of them do not want to talk to designers face-to-face or, oftentimes, if they do, they use some expressions in their speech that are clearly disconnected from their emotions or their real feelings. So, at this moment of our research, we needed a tool to help us to have a deeper understanding about this community's needs, dreams and wishes. In the next paragraph, I am going to explain the use of probes in our research, and why we chose it.

In creating probes, we used whatever secondary sources there were about Vila Rosário. Most notably, there was Dr. Costa Neto's book (2002) (Figure 3.1). Also, we interviewed people who had been working in Vila Rosário through Skype. These interviews were mostly done with doctors and other health care professionals who could be accessed through our network of contacts in Rio de Janeiro.

> "Another efficient way of getting a grip on the subject is an interview with an expert or a key person, which can help to outline the issues raised by the study, and to get in touch with appropriate people (for more instructions, see Millen 2000). Expertise helps to get a comprehensive idea of the phenomenon, and to direct and focus attention on essential users and areas of experience". (Mattelmäki, 2006)

FIGURE 3.1
Inspiration for probes

Setting up the research / intervention
Documental and bibliographical analysis; Interviews; (re)formulating objectives; choosing approach (methods and techniques); Negotiation: sending a research plan.

Preliminary mapping
Mind map: to get a view about issues of the context.

Based on key concepts we got from the pre-understanding phase we started to build the mind map. Our objectives were to identify and consolidate previous knowledge about the subject.

A mind map is a graphical representation of concepts or ideas, and it helps to recognize patterns, see and classify relationships among concepts, and organize information to identify the main ideas. This visual technique, developed by Tony Buzan (Buzan & Buzan, 1996), helps to: (1) make abstract ideas visible and concrete; (2) connect prior knowledge and new concepts; (3) provide structure for thinking, writing, discussing, planning, and reporting; and (4) focus thoughts and ideas that lead to understanding and interpretation. With the mind map we could share and communicate ideas, both verbally and visually, to the specialists that are in Brasil.

For us, the probes were the first contact with the reality of Vila Rosário. Mattelmäki (2006) stresses the necessity to have

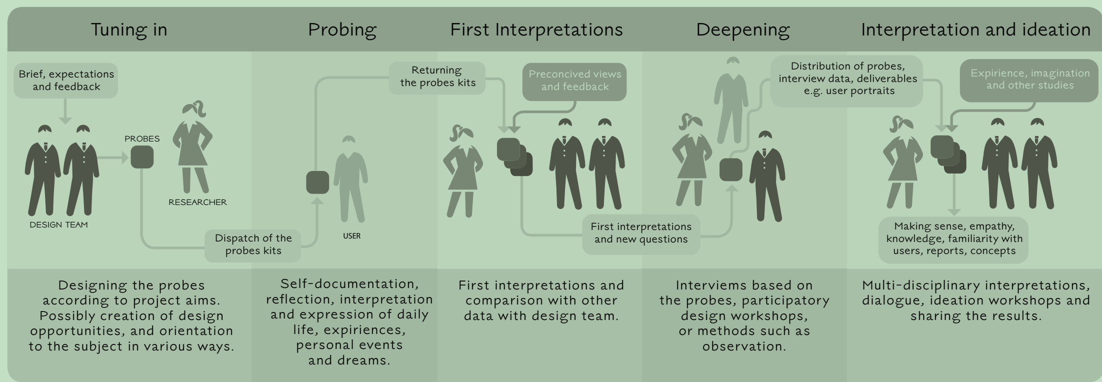
the users' commitment and participation, giving data to feed designers' inspiration. The user's participation will help designers to have insights and to develop design solutions adequate to the context's reality. The probes materials are typically communicative, visually interesting and easily approachable, as well as specially directed for the users, writes Mattelmäki (Mattelmäki 2003: 123).

To Mattelmäki, the probing process has a few clearly defined steps. In contrast to Gaver, Dunne and Pacenti's original work on cultural probes, she sees them as interpretive tools (Figure 3.2).

According to Mattelmäki (2005), probes aim to invite and/or provoke users to reflect on and verbalize their experiences, feelings and attitudes, and to visualize their actions and contexts. In our "experience for health", especially in poor communities, it is necessary that we use something enjoyable to invite them to dream and to share their feelings and dreams with us.

Mattelmäki (2005) maintains that we can identify four reasons for applying probes: Inspiration, Information, Participation, and Dialogue. These are powerful reasons for applying probes in our communities. We need inspiration to provide new insights, and information to know more about needs and experiences in an emotion-

FIGURE 3.2
Empathic Probes
(Mattelmäki 2006)



al and provocative way. We need participation to understand real needs, especially in communities that want to integrate the design process, and we need dialogue to create a direct and real interaction between our communities and us, to avoid misunderstandings in our communication.

We did a fairly standard package of probes consisting of a disposable camera, postcards, diary, visual questionnaire, and a greeting card from us (Figure 3.3). The probes are explained in detail in Marcelo Judice's doctoral thesis. The package was delivered to Health Agents in Vila Rosário, and after about four weeks, they were returned to us in Helsinki, where we used the probe returns as material for our field work in Vila Rosário.

The probes were analyzed in a workshop in Helsinki. They helped us to gain inspiration, to identify design opportunities, and to obtain an empathic understanding of the community members' needs and dreams. This necessity was underlined in the Health Agents' talk: "We want you to understand that we really want to change our situation, but we want these changes in our perspectives, not in yours." For that reason, it is clear that we need to have a deeper understanding of what the communities' members expected from our work and what kind of health situation they dreamt about.

Finally, probes were chosen because they worked well in this phase, when our design focus was open. It was important to gather inspirational, visual and empathic material for getting an

TABLE 3.1. THE PHASES OF PROBING BY MATTELMÄKI	TUNING IN Design of probes according to project aims; creation of design opportunities, and orientation to the subject in various ways; participants selection.	SENSITIZATION Self-documentation, reflection, interpretation and expression of daily life experience, personal event and dreams.

idea of Vila Rosário, not for defining new concepts or products. For us, probes were sensitizing devices in a situation in which we had to work from afar. As this community is a "hidden community", outsiders are not able to go there without guidance. It is not easy to reach some places, and some places are very dangerous, especially for outsiders. Probes helped us to know Vila Rosário better, before we went there.

FIGURE 3.3
Probes package: contents

FIRST INTERPRETATIONS
Comparison with other data with design team/ workshop: researchers and design team – Finland.

DEEPENING
Interviews based on the probes, observation, storytelling...

PROBES

4

Vila Rosário, the Ambulatory, and Community Health Agents

52
The Ambulatory:
Physical Space

57
Health from the Health
Agents´ Point of View

62
Working as a Health
Agent in Vila Rosário

66
FAP, Doctors and
Health Agents

71
Health Agents' Tasks

It was a sunny Wednesday in Rio de Janeiro, when Marcelo and I had booked our first meeting at Vila Rosário[4]. Despite all the preparation we did before coming to do our fieldwork, there were some "butterflies in the stomach". The idea of talking to the community's members, interacting with them, taking part in some moment of their lives was like a new beginning for us.

At 2pm Dr. Castello Branco drove us to Vila Rosário. On the way it was possible to talk about Vila Rosário's project. Marcelo and I had our focus also on the route, but were curious about the itinerary. We had a mixture of feelings in our minds: the fear to pass through streets frequently cited in news headlines; places that the media considers extremely dangerous; watching

on TV shootings and fights among drug dealers from different "favelas"[5]. At the same time, we felt anxiety about knowing some of the inhabitants of Vila Rosário, about understanding more about their lives, and about being in the context we were familiar with from secondary sources and probes only. Vila Rosário is indeed a very distant place from our middle class reality.

During the journey, the car passed nearby some favelas. Facing this scenario Dr. Castello Branco starts to talk about issues these communities deal with, which can affect the society as a whole. Problems like sewage, crime, lack of proper facilities for the disposal of sewage, poor standards of hygiene, poor diet, lack of education, and so forth. Castello Branco identified two main issues as important issues to be approached: garbage and environmental (ecological) problems. In slum quarters located in hills for example, people are cutting trees and hence deforesting the land to build new houses without having the necessary skills to complete the tasks. They are doing this in a disordered way. They do not think about (or better, do not have the understanding of) environmental consequences. Trees were burnt or cut having as consequences increased soil erosion, risk of flooding and landslides. For example, houses "are dragged down" by rainfall and sometimes rocks fall over houses or onto the streets. After the rainfall, the flood in some areas forms a perfect environment

4
Vila Rosário is the name the Society of Fine Chemistry to Fight Against Tropical Diseases - QTROP society gave to designate an area larger than only Vila Rosário's neighborhood. They call the area "The Great Vila Rosário". The region where the Vila Rosário's program is implemented is a territory situated between the rivers Sarapui and Iguaçu. To the East is the railway line that connected the Rio de Janeiro downtown area to Guapimirim and west with the Belford Roxo Municipality. Costa Neto (2002)

5
Favelas mean squatter settlements or shantytowns, called "subnormal agglomerations" in the census. (Perlman, J.E. 2007)

FIGURE 4.1
Route from Barra da Tijuca
to Vila Rosário

3 parallel avenue to one of the main tracks of the international airport of Rio de Janeiro
2 Alves Nunes street in Duque de Caxias
1 Sarapuí river with Avenida Presidente Kennedy, at the beginning of Vila Rosário. Route from Cosme Velho to Vila Rosário: Through Christ the Redeemer (Cristo Redentor), an important and well known touristic point of Rio de Janeiro – Bus station to give a ride to volunteers from the Vila Rosário project. We can observe in the map, from UFRJ the route is the same from Barra da Tijuca.

for some diseases. The garbage that is spread all over the place by the dwellers is another source of disease.

After 25 minutes of a trip through wide avenues with a calm transit, we were facing the Federal University of Rio de Janeiro (UFRJ)[6]. Suddenly we were passing parallel to one of the main tracks of the international airport of Rio de Janeiro, going to Duque de Caxias (Figure 4.1 , #3).

Arriving in the main avenue of Duque de Caxias, we faced a very crowded city, paved streets all around. Everything that we can imagine existing in a developed city we could find there. On Alves Nunes Street (Figure 4.1. #2) we could see good business marketing, many people walking around and shopping a lot. Ten minutes later, about 5-6 km from this street, we could see the beginning of Vila Rosário – an area of approximately 30 km^2, situated northwest of the confluence of the Sarapuí river and Avenida Presidente Kennedy (the main avenue of Duque de Caxias) (Figure 4.1, #1). In Cunha's sense (2005) Vila Rosário should not be considered a periphery community (areas far from the city's centre).

From the moment Vila Rosário came into sight to the moment we arrived at the Ambulatory we were all silent. We were thinking about the data we received and collected from Vila Rosário, a poor community, with low access to health care, somehow with low education level to take part in the local labor force, and so on.

Duque de Caxias is the second richest city in the State of Rio de Janeiro[7]. Costa Neto (2003) has written on the subject:

6
"UFRJ is the largest federal university of Brazil, where state-owned universities are the best and most qualified institutions"
http://en.wikipedia.org/wiki/Federal_University_of_Rio_de_Janeiro

7
http://en.wikipedia.org/wiki/Duque_de_Caxias

Vila Rosário is located on the second district of the city of Duque de Caxias (region of Gramacho). Situated, therefore, in the center of where the recent governmental statisticians had extracted the alarming numbers of detected cases of tuberculosis, corresponding to a real tax of 103 cases for 100,000 inhabitants. In the same region, few kilometers from Vila Rosário, we can find a huge petrochemical complex. The complex includes, for example, Petrobras' REDUC refinery, where they process 120,000 barrels of oil a day. This region generates millions of Brazilian Reais per day.

The economic dynamism of Duque de Caxias is one of the factors that stimulate its population growth. This growth can be connected with migratory flows. The majority of Vila Rosário population is composed of migrants from other states, that certainly came to the city of Rio de Janeiro in search of the El dorado[8]. (Costa Neto 2003)

Vila Rosário is not characterized by geographic isolation, but still has the same problems from rural communities: small or no access to economic opportunities, little access to basic social services (running water, quality public education, access to health systems etc.). Why this disparity among pockets of wealth and prosperity and a pocket of poverty, separated only a few kilometers? Both pockets are built by Brazilian citizens, people from the same country, having the same government, so why does a situation like this happen?

After 47 km and 46 minutes of a very pleasant trip, without any accidents or shooting[9], we arrived at Ambulatório Paroquial Irmã Beta (ASPAS)[10].

THE AMBULATORY: PHYSICAL SPACE

As soon as we arrived we were invited to explore the place. First, we wanted to understand more about the physical space and

the activities they have there: where and how the activities are organized; what are the main objectives to develop the activities; who are the people involved in the activities; what artifacts are necessary to develop the activities; which important points to be improved in workshops and so forth. Second, we wanted to understand how the activities happen; what kind of feedback the Vila Rosário Institute is having; statistics; and so forth.

In the kitchen garden (Figure 4.2-1) and in the kitchen (Figure 4.2-6) it is possible to visualize two key-spaces to the project. During the probes workshop in Helsinki, Marcelo and I had started to create our design drivers, and one of the ideas was a nutritional workshop with different levels of information: food cultivation, food preparation, food hygiene, food storage and so on.

We can consider the kitchen garden as a potential place to teach people how to use the soil to obtain food and medicine. We are not assuming that all the nutritional balance needed and medicines to prevent or fight diseases are going to be cultivated in this kitchen garden. We were seeing these solutions as a beginning to improve people's situation. The space for the garden is 10 meters per 50 meters (500m^2) (Figure 4.2-1).[11] To cultivate the plants people need small spaces, they can cultivate these without bigger difficulties, and the cost to do it is low. The plants can

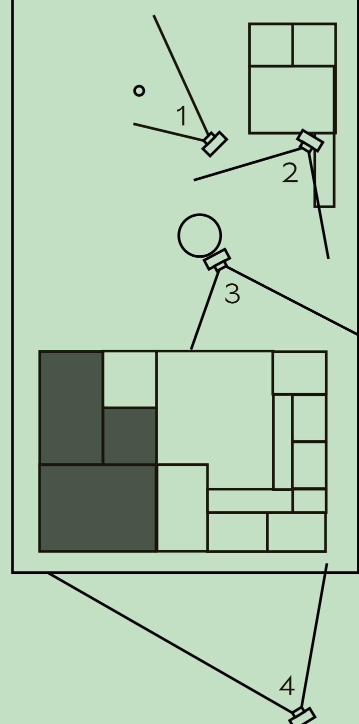
8
http://en.wikipedia.org/wiki/El_Dorado

9
I am not assuming that this route it is always safety that shootings didn't happen. I am just saying that our trip was calm, despite our fear and anxiety.

10
The ambulatory (ASPAS) was inaugurated in 1978 by sisters of the Divine Will from the City of Bassano del Grappa in Italy, having as a mission to take care of the human being in its entirety. They have as main objective, giving social and health support to community members. (Costa Neto 2002). Currently, the Vila Rosário Institute has its own rented building, next to the Ambulatory.

11
Costa Neto (2002)

1 Kitchen garden

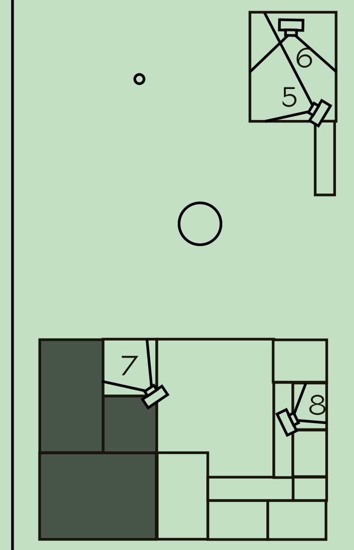


2 Eating time at patio

3 Embroidery at patio

4 Ambulatory´s façade

5 Workshop´s Office (2nd floor)



6 Kitchen (1st floor)

7 Multiuse room

8 Administrative room

FIGURE 4.2
In this figure I am trying to show some key parts of the ambulatory and the position of the cameras during the field work

help, then, to improve nutrition so that all the necessary elements for good functioning of the body can be supplied. In consequence, people will have good defences against various illnesses (Costa-Neto, 2004).

The kitchen (Figure 4.2-6) is a space where the nuns are preparing some medicines and special flours to complement the lack of vitamins, especially for children and mothers that are breast-feeding their babies. The kitchen is very functional and has all the household goods needed to develop a good training. In Figure 4.2-6 it is possible to see the Health Agents preparing snacks for the coffee break.

During the coffee break (Figure 4.2-2), we were talking to the specialist and the nuns. They confirmed that food is good motivation for people to take part in activities. Another point they underlined was the necessity to have a space for children. Most of the participants are women and they usually have no space for leaving their kids, neither nannies nor babysitters to leave their children with.

During the coffee break, Drs. Castello Branco and Costa Neto asked us if we knew how they started the trainings and why they chose the craft areas to be approached. Although we remembered the story in Dr. Costa Neto's paper (2004), we wanted to listen again. This is what they told us:

In 2004, they had a meeting at QTROP (a Chemistry Society for fighting Tropical Diseases) where 31 participants from QTROP and from Vila Rosário took part. Together, based on some criteria and diagnosis, they did a list of 20 potential activities[12] to be chosen by people from the community to be approached

12
To know more about all the activities and how they proceed to choose these activities refer to Costa Neto (2004).

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 sewing, embroidery, and related courses (all females), herbalism[13], mosaic, woodcraft and ceramics. They started the program based on 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.

According to Drs. Castello Branco and Costa Neto, the process of inhabitants being committed to a project like this is very slow. In their opinion, this situation is comprehensible, as a process like this requires new habits. Residents often are not ready for changes. But when they see their neighbours taking part in the courses, and later earning money, and as consequence changing their habits and improving their lives, they start to get involved in the projects. Freire (2005, 1996) considers the situation of vulnerable people when facing the opportunity to improve their lives a hard job. People need to re-adapt themselves to a new situation, a different condition from the old one they are already immersed and adapted to. Often they “feel themselves incapable of running the risks it requires”. Costa Neto also stresses that to do this kind of project, specialists should be realistic and have in mind that the inhabitants’ “energy of propulsion” is to earn money, and to do so, the inhabitants need education and training.

Embroidery training took place at the patio (Figure 4.2-3). Workshop’s Office (Figure 4.2-5) is located on the second floor, over the kitchen. During the fieldwork we also ran into one of the multiuse rooms used for some activities with the health agents and some stakeholders (Figure 4.2–7). In the computer room (Figure 4.2–8), it is possible to see the only computer they have in the Ambulatory, and the computer is more related to personal use of the nuns than other activities. The nuns allowed

the stakeholders to train the Health Agents and to fill the forms in the computer, but the room was not fit for this purpose. The picture was taken during the training of the Health Agents. We can see that training is collective: all agents are around the computer and are given advices or tell stories about their experience with devices. One place that needs to be redesigned is the computer room.

HEALTH FROM THE HEALTH AGENTS' POINT OF VIEW

Marcelo and I tried to understand what it means be "in good health" for the Health Agents. We placed ourselves in a circle and started to talk about health freely. Health Agents started to discuss their opinion about Health. In Clara's opinion, health is the physical welfare of the person, to be well fed and to feel strong to work. Custodia complemented Clara's though by saying that in Vila Rosário, this concept needs to be more concrete, and all of them agreed. In her opinion health is a set of things. For example, if a person is having financial problems his/her health does not go well too. Custodia wants to make her opinion clear to the others:

1 In my case, for example, If I am without money I will start
2 to get stressed, and I will start to have one problem after
3 another (it's like a snowball). Therefore, according to
4 this point of view health means to have an income.
5 However, as I work in the health area, I know that this is
6 not an isolated issue; I know that the misery brings
7 illnesses! Including those illnesses that had already been
8 eradicated.

13
"Herbalism is a traditional medicinal or folk medicine practice based on the use of plants and plant extracts. Herbalism is also known as botanical medicine, medicinal botany, medical herbalism, herbal medicine, herbology, and phytotherapy". http://en.wikipedia.org/wiki/Herbalism

In lines 3, 5 and 6, Custodia stressed that income is the starting point for illnesses. She also points out that the situation is like a "snowball" for the Health Agents. To be healthy means much more than having an income. To be healthy also means added income and education.

As it is possible to identify in Health Agents' discourse, to be educated means not only to receive formal education, but all kinds of experience from which the person can learn from. Learn values, behavior, learn a profession. In this case, if a person is not educated she will not be able to integrate the workforce, as consequence will not have an income; she will not be able to clean the house in a right way; she will not have the adequate personal hygiene, and so on.

There are many more subjects involved in this health scenario. For Health Agents, health is not connected only to the sequence: finding the illness, treating it, and as a result have the cure. The sequence, however, is not so simple. It is important to consider other features of the patient's life, such as nutrition, environment, education, and so on; is also important to consider the patient's family and his/her friends. For them, health is a concrete social matter, that needs to be approached as a whole. Leila starts to draw a scenario for us:

1 In our community, everything is based on a set of lack: it
2 lacks feeding, it lacks education, it lacks income, it lacks
3 information and because of this lack of everything, we have
4 the illnesses... Thus we (health workers), in ours walks by
5 the community, we try to bring orientation, information for
6 the needed people of the community.

In this point of the conversation, it was interesting to notice Leila wanted to talk about the responsibilities of the Health Agent (lines 3, 4, 5) . She wants to demonstrate the importance of the Health Agents as people that know the methods of spreading

information among people. Also, she shows that they know which places they should go, to make the information accessible for the community. In this excerpt it is clear that Leila wanted to change the focus of our conversation from defining health, to the Health Agents as key persons to help in the implementation of the design ideas. During that time, Marcelo and I were doing the presentation of our work; we highlighted the importance of finding key-persons inside the community to help us.

During this moment with the Health Agents, it was interesting to observe their behavior. First Custodia and Clara focus on answered our question: "what does health mean in the Vila Rosário context" (the concept of health for the inhabitants). Custodia was telling her experiences not only as Health Agent, but also as one of the inhabitants of Vila Rosário. Clara approached stories about food and lack of work in a subjective way, focusing on the idea of income: without income, we cannot afford food. She was telling stories and doing observations clearly to justify and highlight Custodia's point of view; after all, Custodia had stressed lack of money as the first step to be ill. Clara was showing us that she is a Health Agent who works as a member of a team.

In contrast, Leila was keen to show the importance of Health Agents' work, showing a behavior disconnected from the other agents. Other Health Agents were talking about a health context and showing examples of their own lives to exemplify. They highlighted that as they are a part of the community, they have a deep understanding about health in Vila Rosário and its implications on the community's social life. On the other hand, Leila was placing the Health Agents on the specialists' level. At this point on our conversation, we had the impression that Leila wanted us to get the message she has been sending to us since we arrived. Therefore, she starts to speak again:

1 An important point to highlight for you is that the
2 relationship among members of Vila Rosário community is very
3 different from the relationship people who live in the urban
4 place have. In communities like ours, the people help each
5 other frequently; all the neighbors know and speak to each
6 other. They really want to help the other! Maybe because of
7 the inadequate or no income, for the hunger, for the lack of
8 information or for other factors, they are really connected.
9 This link, this mutual aid is a very important point for us,
10 Health Agents.

We thought that here, Leila was defensive, and tried to change Marcelo's and my opinions. According to her, we had constructed a bad perception of Vila Rosário. "Bad" in a sense of dire situation; in her perception we could be so blind trying to focus just on very serious or extreme scenarios that we were not able to see the good things they have there (lines 1, 2, 3, 4, 5, 6). At this moment Leila changed her position from a "between" person to an inhabitant of Vila Rosário, showing their values and the fact that they are being proud of being a part of the community (line 6).

In Leila's comprehension, the impressions we have about Vila Rosário were based on papers, media, and interviews by Skype, MSN or email, methods that cannot show all the reality of the context. The media in particular prefers to underline the complex situation of poverty, violence, drugs, and so forth. Scientific papers also usually focus on the challenging aspects. Based on this, Leila wanted to show us the nice side of Vila Rosário.

As the health context in Vila Rosário is very disconnected from the mainstream society, Leila could not find so many good points to highlight, but in her opinion, this is part of the project we are taking part, so she decided to emphasize something important and positive from her society. For her, we do not find these sides of Vila Rosário if we look at it through our middle-class backgrounds: the persons at Vila Rosário are connected to

each other; their values are based on relationships and mutual help (lines 2, 3, 4, 5). For us, her objective was to tell us that to see Vila Rosário properly, we need to identify positive qualities as well (lines 6, 7, 8, 9, 10). As Marcelo and I already have good data to build the meaning of health in Health Agents' point of view, we decided to follow Leila's thoughts. And she continues her turn:

1 To "find" ill people or people that are in need we have
2 to be connected with people. Sometimes the neighbors tell
3 us that there is somebody sick; sometimes the person comes
4 to see us; sometimes we can identify the situation of the
5 person by ourselves, during our walking through the
6 community. When we see an unusual situation, we go to the
7 person or to his/her family and we check if they need
8 something, how is their health situation, how they live,
9 and so forth.

In this excerpt is possible to identify three different ways Health Agents identify illness: gossip (lines 1, 2); the ill person approaches the Health Agent (lines 3, 4), and the active search (lines 5, 6, 7). As Marcelo and I had approached the Health Agents and the specialists about active search and about situations where the ill person came to ask help, we asked the Health Agents to explain more about gossip in the community. They said it's very common in the community for people to talk about other people's private lives.

For Health Agents the gossip is important, for example, to find out more about the health situation. They can hear about issues like: food, hygiene, illness, unemployment. Health Agents see the gossip as an opportunity to track the illness or to find a situation they need to work with. When Health Agents are there paying attention to the gossip (or maybe, having a good gossip moment), they can perceive people demonstrating different emotions when gossiping; they say and express things that they would not do if they were inquired about. Based on it, Health Agents can have a

better understanding about the actual situation of the community. For example, they know it is difficult for a person with tuberculosis to look for help from outside. It is easier to get help from Health Agents, who are people from the community and can spread the information about their illness. In Health Agents' opinion, because of the lack of information people at Vila Rosário often isolate sick persons, especially if they are suspected of having tuberculosis or HIV. And one way to express this discrimination is through gossip. Another example is the families or friends of a sick person who start grapevine because they do not know where to find help, or what attitude they should have to improve their health. They are feeling themselves uncomfortable with the situation; they are worried about the situation, so they use the gossip act to express their anxiety. According to the Health Agents, through gossip they can find opportunities to improve the health context at Vila Rosário.

WORKING AS A HEALTH AGENT IN VILA ROSÁRIO

In this section I am going back to the topic of the health agents' work. This question was part of my discourse many times during our fieldwork: "What is your job as health agents? Or what is the Health Agent's job?" the beliefs health agents have, their considerations about what is fair and acceptable, the manner they respond to the community's needs, their perception about their own work.

Ever since we arrived at Vila Rosário, Leila was keen to talk about this issue, so I am going to start with her thoughts. According to her, health agents are people who try to bring information for people of the community. She attached great importance to the fact that, sometimes, they have to have an "*assistencialista*"[14] attitude to do their work in a proper way.

1	Leila:	Even if we don't want to have this behavior what can
2		we do?
3	Andrea:	but why do you think the "assistencialismo" doesn't
4		work?

In the quotation above I had asked Leila about the efficiency of the *assistencialismo* conduct in her work (line 3, 4), because myself and Marcelo were sure that she had not chosen the correct term to describe health agents' actions. She was not feeling herself comfortable to talk about the issue applying the term *assistencialismo,* but she is truly proud about her work as a Health Agent and the way the health agents do they work, as she told Marcelo and me when we arrived in Vila Rosário. Yet, in our opinion, they don't do *assistencialismo,* they do more than give assistance to people. To check our opinion I decided to go deeper in this issue:

1	Leila:	The problem of the "assistencialismo" is that some of
2		the people that receive food, clothes, etc for free, do not
3		give value to these things, or worst, they think that is our
4		obligation to be giving these things to them.
5	Andrea:	So, as health agents, you see the community's
6		members as citizens who need to change their attitudes,
7		their behavior. I can say that you are like agents that
8		"flash" to transform the situation. What I mean is that
9		the concept you have about "help the other" is a concept
10		based on giving education, providing information and not
11		giving money. Am I correct?
12	Leila:	Yes, you are correct. However, if we arrive in a
13		house and the family is starving, what can we do?

It is interesting to notice that after we had gained some time of familiarity with the context, Leila had changed her perception of her work as health agent. We can identify

14
To give assistance, synonymous to charity: giving money, food or help free to those who are in need because they are ill or poor. " The 'assistencialismo' is the opposite of Freiriana's pedagogy." (Streck et al. 2008).

in her talk that her opinion about being a health agent was transformed by the way of thinking of of Vila Rosário project's specialists. She has appropriated some of the terms (jargon) and thoughts from the specialists and incorporated these in her perception. Not only in her conduct as health agent, but as a person from Vila Rosário as well.

This adaptability[15] of her behavior and thoughts seems like an alternative to becoming a specialist. In the cultural probes, she had written that she wanted to graduate in social service and continue to work on Vila Rosário Project. This "adaptability" seems to be a way to show (or maybe to prove) to the specialists that she can be part of "their group". The fact is that, as she is not used to some terms, she is applying these in an inappropriate context. For example, in lines 1, 2, 3 and 4 she describes the assistencialismo conduct in a very good way, and she is underlining that they want to change this habit from the community. However, when I inquired her about the situation (lines 5 to 11), she answered me with a question that raises fears of doing assistencialismo instead of being given assistance (lines 12, 13). Once more, she is about to discuss the issue in a "specialist" way, instead of using her emotions or feelings. In the moment I was inquiring Leila, Custodia decided to give her opinion about the subject:

1 Do you think that in a situation like that we are going just
2 to give information? The person with hunger does not even go
3 hear us! First, we have to "treat" the hunger of these
4 people, later we can start to make something! To educate
5 them.

In contrast to Leila, Custodia is not worried about choosing the correct term, she just wants to show Marcelo and I the reality (lines 1, 2, 3), how the health agents work the situation (lines 3,4) and how they intend to change it to improve the community

(line 4). Custodia just wanted us to understand her feelings about the situation. After Custodia's clarification, Leila felt herself more comfortable and started to show her feelings. It was very interesting to perceive the difference in her behavior, as soon as Custodia finished her talk; Leila raised her intonation and told *"Right!"*, and smiled. It looked like she was finding something new. In this moment everybody gazed towards her, and she told in a very happy way:

1 But, when the person starts to get better, when he/she can
2 obtain food by him/herself, we change our "assistencialista"
3 behavior. Of course, we still work with the patient,
4 supervising the treatment until he/she becomes healthy again.

Leila does not allow herself to act as an "ordinary" person from Vila Rosário (lines 1, 2, 3, 4). In another meeting Marcelo and I had commented to Castello Branco and Costa Neto our observations about Leila's behavior, not being herself, trying to use "more scientific jargons", to show a self-control, using a more strict body language, and been very polite. Her behavior was affecting her stories, her values and worst, was affecting the other health agents' behaviors as well. Some health agents started following Leila's behavior, using unfamiliar terms, and thus adopting an "outsider" pose. The interesting point was that Costa Neto underlined that the specialists tried to do the opposite: they preferred to use "ordinary" language.

Costa Neto brought himself to the discussion, and explained the situation based on a very popular proverb: "Give a man a fish and you feed him for a day. Teach a

15
I am not going to affirm that it is a transformation of her behavior. I could identify many moments when she had a conflict about her ideas. Sometimes she wants to show the community context and highlight that she is part of this context, and we can see that she is particularly proud of it. However sometimes she has a talk that makes her very distant from Vila Rosário's reality, she is acting like an outsider.

man to fish and you feed him for a lifetime". He explained that their philosophy is to guarantee resources over time. The model they follow does not encourage dependence. It is the opposite, they are trying to empower the community[16]. So, they do not do *assistencialismo,* if we follow Costa Neto.

Deolinda, who had been listening to the conversation until this moment, decided to talk. She highlighted our question "What is your job as health agent?" and begun telling us that people need to have energy and disposition to work as health agents. To be a Health Agent is not only to deal with the illness. In the work they have, for example, to give baths, call ambulances, and sleep at patients' homes to accompany them. Deolinda told us a story where she needed to spend one night in a queue to try to book an appointment for a patient. One point she highlighted as one of the hardest parts of their work as health agents is when the patients, and sometimes their families think that health agents need be responsible for the patients and also their families' lives.

Custodia agreed with Deolinda's opinion and added her thoughts. In her opinion it is important to do things like do haircuts to avoid lice, to sew clothes, to teach people how to clean the house, and so forth. Despite the health agents' work main focus being on tuberculosis, their personal objective is to improve the community's life. To do so, in Custodia's opinion, the health agents need to act in the best interests of the people in the community, giving examples of a good and healthy life through their work. Dulcinea, another health agent, said that she could tell us stories to about what it is to be a health agent at Vila Rosário, , but she could not talk about her work in one phrase.

FAP, DOCTORS AND HEALTH AGENTS

When Drs. Castello Branco and Costa Neto told us more about the project, we began to understand health agents' work better.

Dr. Castello Branco said that the health agents work for Instituto Vila Rosário, but Ataulfo de Paiva Foundation – FAP pays them. 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 not-for-profit foundation, so the money that it collects is used for works like this intervention in Vila Rosário, or for technological improvement.

FAP has an interest in the prevention of diseases. This means, to prevent that other people get contaminated. Furthermore, this is what health agents do now: they approach the ill person, direct the person to the Health Center (if necessary), follow up the person's treatment, and give support to the person and the family. Therefore, they are preserving health in the whole community. The Secretariat of Health takes care of the patient, and they do this in a very efficient way. The health agents' work is a complement to the work of the Secretariat of Health. Dr. Castello Branco added that the work health agents are doing

16
We had the same discussion in Windhoek during the potentials 2 workshop (to have more details about the workshop see chapter 10). We have made clear that our work is not charity. We need to shift from the charity model because the charity model offers no supply or resources guarantee overtime. Its model works just for a period of time. And the worst aspect of charity model (that just gives for free and do not teach the people how to do by themselves) is that this model disempowered people, they loose their sense of pride. Charity can leads or encourages dependency. In a sustainable model we need to teach how to fish and teach how to take care for the resources. As Paulo Freire assumes: "False charity constrains the fearful and subdued, the 'reject of life', to extend their trembling hands. True generosity lies in striving so that these hands – whether of individuals or entire peoples – need be extended less and less in supplication, so that more and more they become human hands which work and, working, transform the world."

is very important. As a doctor, he does not have time to treat his patients and at the same time treat the community, but with health agents' support, he can help to design projects to treat the community as a whole. He needs to have an agreement with the health agents. At this moment, it was easy to see smiles in health agents' faces. They felt themselves proud about their work. As Dr. Costa Neto underlined, despite the FAP motto of being "Brazilian League Against Tuberculosis," the specialists involved in the project do not believe in a micro approach. Rather, they try to fight the disease in a scientific way, without considering the context as a whole. In contrast, Drs. Costa Neto and Castello Branco believe in a holistic approach.

I have been wondering whether it is correct to say that the intervention at Vila Rosário is a qualified intervention in the community's daily life. Health Agents are contributing to the rescue of citizenship and trying to make human rights something real, not abstract.[17] To my surprise, Clara and Dulcinea (two Health Agents) answered me in a very fast and enthusiastic way. I was surprised because when I talked about citizenship and human rights, in my "stereotypical" opinion, the specialists were supposed to be more connected to these themes. It was my mistake. Some agents are really prepared to recover the community from the apathy widespread among some community's members. Clara's thoughts were so connected to reality that, to me, she was like a politician speaking to us. In her opinion, the poverty condition in Vila Rosário has as main consequences deprivation and exclusion. She was talking about deprivation of their self-esteem, of their dignity, and of their exclusion from mainstream society.

Clara's perception of the work of a Health Agent is that it is hard, with some failures and some successes. She said that even though she had just started to work as health agent one month

earlier, she knew exactly what it means to her; she is part of the community. Despite their title "Health Agents" they are more like "Wellbeing Agents". Through Vila Rosário project, Health Agents are trying to provide access to resources (education, food, hygiene, environmental care, health, and so on). They are trying to change the condition from stigmatization to a life of participation. They are trying to be a part of the community in order to heal it. The Health Agents are the key persons to spread these thoughts and actions among people. According to her, the majority of community members are connected, they are used to helping each other and to be worried about each other. Most importantly, it seems to me that they had started to identify the Health Agents as key persons to make Vila Rosário self-sustainable.

Deolinda has the same opinion about being a key person in their society. She was telling that when people know that she is a Health Agent, they ask her for help. If they know that a neighbour has symptoms of some illness, or if someone believes that another person has some illness symptoms, they also say to the person to go and ask Deolinda´s help. Deolinda told that she also gives advice about how the inhabitants can feed themselves in a healthy way; sometimes she helps to do a *layette* (a complete set of clothes, sheets, bed covers and other items needed for a baby), and she even accompanies an ill person to an appointment. For her, being a health agent is to help people to improve their lives.

For the Health Agents, their work cannot be seen as a conventional job. In some of the Health Agents' opinion, in a conventional job the employee arrives at 9 am and already has a flow of action to follow, most of these actions being self-contained, and at the end of

17 http://www.un.org/events/humanrights/2006/

the day, the employee goes home and has no more obligations related to the work. In the Health Agents' job, they are there, in the community, 24 hours per day, 7 days per week. As we could determine during the probes study, people even call them in the wee hours to measure the blood pressure, and to assist mothers giving birth. They perform companionship activities, as they need to accompany people to hospitals, many times having to sleep there to give emotional support to patients and their families. They need to have the ability to bring hope in a situation where people have no more dreams or hopes. They need to have the talent to change and improve the community's situation; they have to make the right choices. Their work is built based on human relationships; relationships that can define the Health Agent's attitudes, values and beliefs, as well as the community's expectations and cultural norms. In Health Agents' minds, the substantial matter of their work is their social responsibility.

Dulcineia, one of the Health Agents, mentioned that even though they felt themselves as key persons in improving the health situation of the community, the situation is not easy for them as Health Agents. In her opinion, some persons still do not know about their work, and some of the health agents have difficulties to explain their work - as she had said, they can tell many stories to illustrate their work, but they are not able to briefly explain the main tasks of their work, in order to convince people to talk to them. In her opinion it was fundamental to develop a campaign to make clear to the population what the Vila Rosário Institute project is for.

Dr. Castello Branco reminded Dulcineia that she works in a richer area, and asked her to explain if she saw differences in richer and poorer inhabitants' behaviors, specially related to her work.

Dulcineia in response explained that in the area she is responsible for, people are better-off, so they often build high walls to protect their houses and install intercoms. She considers this as very important information if we want to understand the inhabitants' behavior and beliefs. To better illustrate the situation for us, she did an imitation of inhabitants talking to her when she tries to approach them about health related issues:

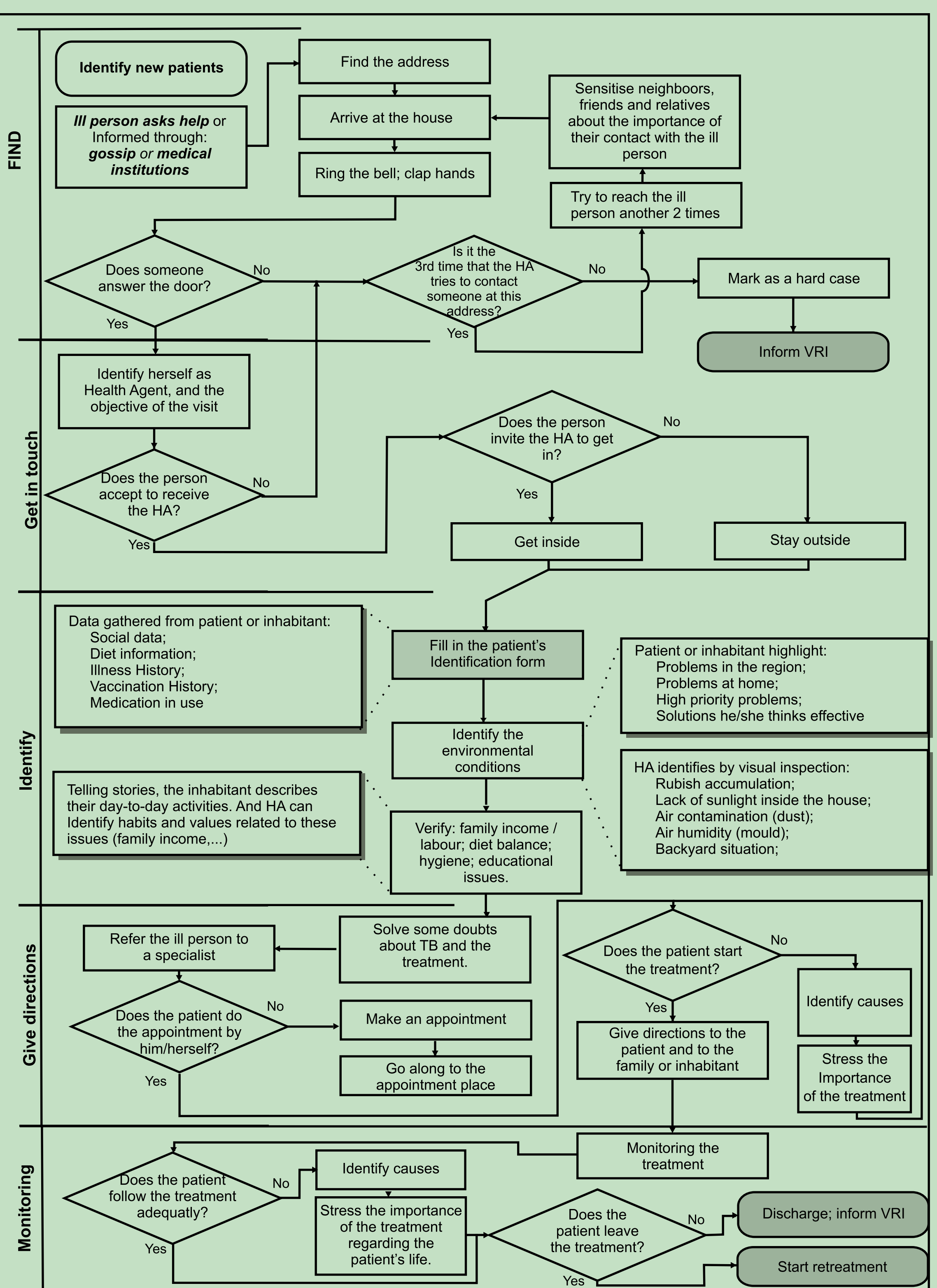
1 "Mrs. We already have health insurance, you don't need to be
2 worried about us, we can afford food, we are not needy
3 people!"

Based on Dulcineia imitation of inhabitants behavior (lines 1, 2, 3) we can see that people see the Health Agent work not as one of clarifying doubts about health issues, but as one of helping needy people. From Dulcineia's point of view (other Health Agents and some stakeholders expressed the same opinion), the majority of the richest people from Vila Rosário do not invite the Health Agents to go in their homes because people are afraid of the violence in the area. Another obstacle to Health Agents is that persons are tired of beggars and sellers ringing the bell of their homes every day, many times per day. According to Leila, people sometimes are rude to her for this reason; people tell her that they will not catch any illness just because they are economically better-off.

HEALTH AGENTS' TASKS

Next I will describe the Health Agents' work flow and illustrate the main steps of their tasks with a diagram. The drawing was based on interviews, observations, and validated with the Health Agents (Figure 4.3).

There are several workflows in the Health Agent's daily activities, including house-to-house screening processes. The



FIND
Identify new patients
Ill person asks help or Informed through: gossip or medical institutions
Find the address
Arrive at the house
Ring the bell; clap hands
Sensitise neighboors, friends and relatives about the importance of their contact with the ill person
Try to reach the ill person another 2 times
Does someone answer the door?
No
Yes
Is it the 3rd time that the HA tries to contact someone at this address?
No
Yes
Mark as a hard case
Inform VRI
Get in touch
Identify herself as Health Agent, and the objective of the visit
Does the person accept to receive the HA?
No
Yes
Does the person invite the HA to get in?
No
Yes
Get inside
Stay outside
Identify
Data gathered from patient or inhabitant:
Social data;
Diet information;
Illness History;
Vaccination History;
Medication in use
Fill in the patient's Identification form
Patient or inhabitant highlight:
Problems in the region;
Problems at home;
High priority problems;
Solutions he/she thinks effective
Identify the environmental conditions
HA identifies by visual inspection:
Rubish accumulation;
Lack of sunlight inside the house;
Air contamination (dust);
Air humidity (mould);
Backyard situation;
Telling stories, the inhabitant describes their day-to-day activities. And HA can Identify habits and values related to these issues (family income,...)
Verify: family income / labour; diet balance; hygiene; educational issues.
Give directions
Refer the ill person to a specialist
Solve some doubts about TB and the treatment.
Does the patient do the appointment by him/herself?
No
Yes
Make an appointment
Go along to the appointment place
Does the patient start the treatment?
No
Yes
Identify causes
Stress the Importance of the treatment
Give directions to the patient and to the family or inhabitant
Monitoring
Monitoring the treatment
Does the patient follow the treatment adequatly?
No
Yes
Identify causes
Stress the importance of the treatment regarding the patient's life.
Does the patient leave the treatment?
No
Yes
Discharge; inform VRI
Start retreatment

main steps described ahead shows a specific search for an ill person, called at IVR as "Active Search".

FIGURE 4.3
Work flow of Health Agents

There are some main steps to their work, from "Finding the ill person" to "Discharge after treatment":

- First the Health Agents identify the need to visit a person that has symptoms of tropical diseases or is already ill. Identification can occur through a neighbour, a friend or someone from the family, who can inform a Health Agent. Also the information can reach the VRI through gossip, or the ill person may ask for help.
- After the previous step, the Community 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. At this moment the exposure is just a hypothesis, so they will do this procedure again after talking to the patient face-to-face. The Health Agents can choose if they go alone, or are accompanied by another colleague.
- 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 the person, they try to contact again.
- Next, they talk with the person and they try to make a diagnosis of the situation (not only of the disease but about the whole situation – house conditions, hygiene, nutrition, and so forth). If they are invited to get inside the house, they are able to see the patient's living quarters. They talk and observe the inhabitants habits – feeding, job, sustenance, conditions of the house, kind of clothes etc.

- They try to identify what kind of illness affects the person and explain the situation to the patient's family and close friends. At this moment they use some material to support their work, for example, booklets about illnesses.
- They fill the VRI form by handwriting, to feed the database with patient's personal data, but also add environmental, nutritional and other important data to have an area profile.
- They mark in the map which illnesses have been found in the house. This is not a standard procedure, but it helps a lot in mapping the spread and the contagion pattern of the diseases.
- 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 follow-up on the treatment. If the patient requires, they will monitor the treatment to be sure that both patient and family are doing everything correctly, and not stopping the treatment too early, which is a real problem, especially in tuberculosis cases. The Health Agents usually follow the patient until discharge. In some cases they follow up even after discharge.

Two particularly interesting points stressed by the Community Health Agents were: the support materials they are using now are not appropriate for their work. The material has drawings that are not connected to the community context, and the content also needs to be more connected 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 Community Health Agents do, they do not even open the door.

This description of the workflow shows that the Community Health Agents have an important social dimension in their work. They are not only persons that are looking for TB cases, or other tropical disease, but they give support to the patient and to his/her family. They also support the community by describing many issues related to the community well-being, and help with issues not related to illness, like child care. They do things that matter directly to people from the community, but need help.

5

Understanding Health Agents in Vila Rosário

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The use of ethnographic techniques and procedures has the objective of developing a detailed study on the activities carried out by an individual or a social group, the existing relations among these activities and understanding how they take place (Nardi, 1997; Suchman, 1991). That is, the ethnography involves the study of people carrying out quotidian tasks that are interacting in complex social environments. The result of this method is qualitative information on these interactions (McCleverty, 1999).

The main ethnographic methods consist of interviews, observation and participatory observation (Nardi, 1997). Interviews can be structured when questions are pre-determined;

flexible or open, when there is a set of topics without a specific sequence; and semi-structured, when there is a set of questions that can drive the interview (Baranauskas, 1999). Observation may be direct or indirect. In the direct observation, people can be observed individually, in real use situation. In this case, the observer makes notes of the behaviors deemed interesting or registers the behavior in another way (for instance, by measuring the time of carrying out a task). The indirect observation is made based on some type of record as videotaping, for instance. (Baranauskas, 1999). In participatory observation, the researcher is involved in the quotidian life of the people under study. This method helps him/her understand and feel the rhythm of the process and the challenges to be studied (Nardi, 1997).

Ethnographic research is used by researchers to "study" the people and their daily activities under the most varied contexts: work, home, schools, laboratories or any other place where they live (Nardi, 1997). It can happen in two ways: in the participants' scenario (or real scenarios – field research), or in the scenario built by the researcher (laboratorial scenarios) (see Suchman 1991). Which way it is done will depend on the specificities of the research.

The ethnographic studies can be registered in format of notes on paper, but also with the support of many kinds of technologies. For example, literature suggests videotaping as one of the kinds of methods that make it possible to extract as much knowledge as possible, about the activities of a person in her social context (for example, Karasti, 1997; Suchman, 1995). That is because videos allow the researcher to view and review the interactions that occur during the execution of an activity. Videotapes help to correct the tendency of seeing what one wants to see or what one thought having seen (Suchman, 1991). Tapes can be used as a way of capturing complex activities that

are carried out in a highly organized site. It can be oriented to the environment, a person, an object, a technologic artifact, or a task under study (Suchman, 1991).

Ethnographic methods are pertinent when the aim is to study why new technologies and products are not welcomed or remain unused. There are drawbacks too. According to Hughes, there are a few restrictions on the use of the ethnography in the design of new technologies (Hughes, 1994). One of them refers to what he calls the scale problem. The ethnography is best used if applied in a relatively confined environment in a small scale. It is easier to concentrate the attention in the participants, who generally are few, and to visualize the differences among the tasks. Another problem refers to time pressure. The ethnography is an extended activity, and serious research of any activity in its social context can take years. Yet, other problems relate to the designers understanding of the results produced by the ethnographic study. Like any other method, unless carefully done, ethnographic research may lead to many kinds of biases.

At the beginning of our work in Vila Rosário, we observed some comments from the community members who were willing to cooperate, that they would need to have greater trust in the researchers. They also stressed that they needed proposals and solutions developed based on their experiences and perspectives, not from a perspective imposed by designers/researchers (see chapter 3).

> Trust is not built overnight; it takes time and considerable effort. It takes even more time and effort when researchers are perceived to be or perceived themselves to be different from the research community in such distinguishing features as gender, social class, culture, ethnicity, race, language, age, religion, caste or role, sexual identity, etc. (LeCompte 2010: 14).

People from communities like Vila Rosário are often stigmatized. People who are not from the community usually see them in a stereotypical way. This type of behavior makes the work of researchers more difficult as community members are afraid of sharing their experiences with researchers. This, obviously, is the case with diseases. Issues related to tuberculosis, hygiene and drug use, among others, can make them believe they will be even more stigmatized. According to LeCompte,

> Researchers must first discover what people actually do and the reasons they give for doing it before trying to interpret their actions through filters from their own personal experience or theories derived from professional or academic disciplines. (LeCompte 2010: 2)

Still, it is important to remember that researchers remain researchers, even when they are accepted by the locals. According to Clifford Geertz, we "cannot live other people's lives, and it is a piece of bad faith to try" (Geertz 1986: 373). However, our method built on empathic design, which gave us a clear identity as designers. It directed us to focus on day-to-day experiences in context, but also gave us a way to position ourselves outside Vila Rosário community. That was the main reason for applying ethnography in empathic design. As Geertz tells, we "can but listen to what, in words, in images, in actions, [people] say about their lives… it is with expressions - representations, objectifications, discourses, performances, whatever - that we traffic". If as researchers we follow Geertz, we need to find ways to convince people in the community to trust us enough so that they can tell us what they really feel like, what the community really is, and what it means to live in it. We have to gain their trust; only after having real trust between researchers and community members, researchers will have real information, which takes us beyond stereotypes.

VALIDATING THE PROBE PHOTOS WITH HEALTH AGENTS: PHOTO INTERVIEWS

After walking around the clinic to analyze the physical space and its implications to the program, Marcelo and I, together with Dr. Costa Neto and Dr. Castello Branco, went to a room to meet the Health Agents. Marcelo and I introduced ourselves; the Health Agents did the same. We reinforced our research objectives and began an informal chat to understand Health Agents' expectations about our work. During the chat, we saw that they were trying to test our knowledge about the probes content. The Health Agents were curious about what we did with data from the probes, and how important that outcome was for us. During the chat, they often referred to probes contents, as if to test whether we really went through the data from the probes, and as if they expected us to have almost memorized all the content.

We had prepared well enough, and passed the "test." To build upon the good atmosphere that had developed, we decided to start the next phase of our research process consisting of interviews based on the probes. We asked the Health Agents to take out the photos and explain the pictures to us.

> "Self-photography gives users an opportunity to document general and detailed information of themselves, their physical environment and lifestyles. The photos can illustrate, for example, their furniture or exercise equipment. When persons themselves take the pictures, the content and the framing of the picture is a subjective choice. The act of taking pictures and seeing the familiar environment through the camera lens stimulates the user to take a purposeful look and reflect on the assignments." (Mattelmäki 2003: 124).

This method proved to be a good way to gain the trust of Health Agents, as it gave them the driving seat. Photographs in Figures 5.1-5.2 were taken by Leila, a Health Agent who wanted

to show us her home street. She was showing variety in social level among inhabitants from Vila Rosário. This family is very poor; sometimes they cannot even afford food; they also lack education and their home is unhygienic. In the same street, Leila lives with her husband. She has a laptop computer, TV, she is renovating her house, and she is doing her undergraduate course. Leila told that these social economical differences are very common in Vila Rosário. The street does not have basic sanitation, nor does it have asphalt either; water is not provided by CEDAE (State Company of Water and Sewer), but it is organized unofficially.

FIGURE 5.1
A mother, her 6 kids and a Health Agent.

FIGURE 5.2
Widow, currently in tuberculosis treatment

In the first picture (5.1) we see a mother and her six children. Each kid is from a different father. The Health Agent told that the woman has more kids, but not all of them are in the photo. The older ones are with the fathers' family. The mother leaves the children to live on the street. She has little control of the children. For example, the kids have no schedule to eat. They eat

when she has money to feed them. The mother does not have a job; she has temporary jobs, when she can find them. Leila was telling us that she already tried to work with this family but it was almost impossible. The mother is a closed person who does not like advice. Yet, Leila thinks she needs to work with this family to improve their hygienic conditions and nutritional habits.

As we can see from this example, in Vila Rosário it is possible to find family forms more disorganized than in mainstream society. By contrast, we can also find families more organized and connected than in the mainstream society. For instance, this is the case of the families of Health Agents Deolinda and Maria do Rosário. For Deolinda and Maria do Rosário, a family has to be connected and live in harmony. Through members of a family, values are transmitted from one generation to another.

When Leila was making these observations, I asked her to explain more about the meaning of not having an adequate feeding in this family context. In addition, I asked her to elucidate why this situation occurs, based on her experience as a Health Agent and a neighbour. I explained to Leila that in my point of view, the lack of income is the key factor to this scenario. She argued against me, though, and told that even if the family had the money they would not know how to feed themselves in a proper way.

1 The mother does not give much attention to feeding. It
2 is easiest for her to go to a place buy candy, soda, and
3 junk food for the children. The kids will be happy to have
4 this kind of food. They prefer junk food to health foods.

Leila underlines that the mother prefers the easiest way to feed her kids over the more nutritional way (lines 2-4). She also reaffirms her opinion that even if the family had money, they would not have a proper diet because the mother argues that she has no time to prepare food and control the kids, who are

also happy eating like this. For Leila, this is a difficult family. She defines a difficult family as a closed family that does not listen to her, or one that does not want to learn more and change their routines. This family has different values and behaviors than the majority of Vila Rosário's families. Leila says that all the neighbors already know the family and their situation, and they pay attention to them, especially to the kids. When the neighbors perceive problems, especially related to food, they support the family with meals. Leila also told that the neighbors who have fruits in their garden always give some to those families. She also says that these kinds of behavior are common in Vila Rosário.

When the children are ill, the mother takes them to the Emergency Room (E.R.) of the hospital. According to the Health Agent, she prefers the E.R. to the Health Center. When I asked her why she thinks this situation happens, she paraphrased the mother:

1 "I prefer to lead the kids to the emergency room because I
2 will receive the medicine for free. If I go to the Health
3 Center I will have to buy the medicines by myself, and I will
4 not have money to buy those. In the Health Center, they
5 never have the medication to give for free, sometimes not
6 even to use in the patient during the appointment".

Clearly, the mother does not trust that in the Health Center she will receive the supports she needs (lines 4-6). Marcelo and I saw during our fieldwork that such opinion was shared widely in Vila Rosário. Inhabitants told us that in Health Centers, sometimes there is a lack of medicines and the patients are too poor to even pay for medicine, so they cannot take the treatment to get better. Sometimes long queues mean that workers in the Health Center cannot admit all the patients. Some inhabitants demonstrate that they believe in people in Health Centers, but they do not believe in the institution. For example, they told

they trust the doctors, but they do not believe that the Health Centers are well prepared to answer the patients' demands.

Figures 5.3–5.4 show pictures taken by Deolinda to illustrate the situation of a widow who lives alone in a one room house. Her husband died recently from hepatitis. His health had been really bad: he had tuberculosis twice and he was a drug addict as well. She has tuberculosis as well. As her husband, she is been treated again from tuberculosis, and she is also an alcoholic. Recently she found a job in a bakery but she had to quit as her illness got worse and she started to feel herself too weak to go out. Now, the Health Agents have discovered that she suffers from osteoporosis. The Health Agent told us that the picture was taken as an example of "one room house", but I can assume that the state of the family's health concerns them greatly: the story was about difficulties, not about a typical small home.

FIGURE 5.3–5.4
The home of a widow with multiple diseases

The woman and her husband's excuse for their situation was the lack of income. When we interviewed her, she told us that her hygienic and nutritional condition is bad because she does not have money. According to the Health Agents, the nuns from ASPAS had obtained an income for the family and had contracted an assistant to guide hygiene and nutrition twice a week. The assistant also accompanied one of the Health Agents every day for a period of time. When the situation started to get better, the family started to have healthier habits, and the nuns allocated the assistant to another case. When the nuns came back to evaluate the family situation, everything had went back to the stage they found before. This situation illustrates that it is not easy to change deeply ingrained habits.

In Dr. Costa Neto's opinion, this family is an interesting case to be analyzed more carefully in a holistic way. Moreover, to understand the health situation of these people and the place the people live, we need to do so, he said. Below we can find Costa Neto adding a complement to the scenario painted to us by Health Agents:

1 They live in what we can call, using a metaphor,
2 a "hole" (as if the person dug a hole and lives inside
3 it). It is common, here in Vila Rosário, houses with
4 only one room, there is no separation for kitchen,
5 bathroom, bedroom, and so forth. For example, last
6 year we had a patient that lived in a house like
7 that. Just one 'room' where the family placed one couple bed
8 and in this bed slept the couple and their four children.
9 Can you imagine this situation? Six persons sleeping
10 in the same bed (1,60x2,00m).
11 He died from tuberculosis. Three of the kids had
12 tuberculosis too. Dona Deolinda was the Health Agent
13 responsible for taking care of all the family.
14 As you can see, in a situation like that we can not
15 think only about the illness, only about the medical
16 treatment and the cure. We need to think about the
17 social connection of this family. We need to analyze

18 the situation in a holistic way. We have to think about
19 the society of Vila Rosário as a whole, therefore it's
20 the social situation of this community that makes the
21 actual situation be like this.

As Costa Neto tells, one-room houses are very common in the poorest areas of Vila Rosário (line 3). According to Deolinda and Leila, inhabitants start building their houses with a small room and later, when they have money, they add rooms to it. In general, the houses do not have ventilation. Usually, there are no windows and there is just one door (lines 1-2). Deolinda, the Health Agent responsible to care for this family (lines 12-13), pointed out the majority of families that live in one room houses have problems with hygiene. Sometimes they have a bathroom inside the house, sometimes they just have one outside, and sometimes they do not have it at all. However, it seems to the Health Agents that some of the inhabitants are used to the situation and do nothing to improve it. In a "one-room" house, they place stove, sink, bed, everything inside, and they use the room to cook, to wash, as a bathroom, and so on.

From the excerpt taken from Costa Neto's interview, it is possible to see that sometimes there are big families living in the cramped spaced of one-room houses. For example, he refers to a case in which six persons used to share not only the same room, but also the same bed (lines 5-10). Based on his experience, Costa Neto once more is suggesting that we should not pay attention to a single variable like illness, but to consider the relation among variables like education, nutrition, hygiene, lack of income and illness to understand Vila Rosário (lines 10-21).

If we go back to Figures 5.3–5.4, we see pictures taken by Leila and Deolinda. The mother and the children of the family who live in this house sometimes go hungry for one week. The mother has no job. She does temporary jobs when she can, but she does

not have energy to work. When she earns money, she prefers to spend it with cookies and guarana[18] (a soft drink from Brazil). Every Health Agent stressed that this is common in Vila Rosário, in which people prefer to buy junk food instead of healthier options. According to these Health Agents, the family is very happy and talkative, even though they live in a situation like this. However, the Health Agents told us that when they asked the family's permission to take the photos they dressed themselves in a proper way and the mother also wanted to brush her hair.

If we look at Figure 5.4, we see that there are no stairs into the house: it is necessary to climb two wood boards to reach the main entrance. There is also garbage all around the yard. The Health Agent described the photos and said that it is a one-room house; there is no bathroom or kitchen. The family sleeps on the floor over some clothes. The children are always barefooted. The mother is a diabetic, has problems with alcohol, and is very skinny. It was very interesting to hear from Deolinda about her health:

1 "The mother had tuberculosis two times, she is diabetic and
2 alcoholic. She is so thin that you can fold her and put inside
3 a handbag! It's easy to see that she is ill! The kids are always
4 barefoot and never comb their hair; the house has no
5 ventilation, no windows. It is a house with a difficult access,
6 as it is placed on a hill. There is a lot of mud, garbage. They have
7 many animals, pigs and hens. All animals are free, there is no
8 proper space to place these animals. They live like
9 favelados[19]"

In Deolinda's description, we can see a hint of a stereotypical view at work. For example, she has made clear to us that she grew up in an era in which to have an appearance of being well,

18 http://en.wikipedia.org/wiki/Guarana#Beverages

19 People that live in favelas.

people should be a little bit overweight. She still believes that if a person is thin, she is not in good health. Tuberculosis is an illness that consumes the body, and one of its consequences is that patients get very thin. In this case, it is correct to believe that the woman is ill and the illness is the cause of her being thin (lines 1-3). However, Deolinda, has done the same comment in many photos, when she was talking about people who were not ill. Another interesting point is her perception of the word "favelas". For her, being a *favelado* is synonymous to a lack of hygiene, a lack of care about their houses, and carelessness about themselves. Again, this stereotype is widely shared in the mainstream society, and members of Vila Rosário are not immune to it (lines 6-9).

While figures above illustrate challenges faced by Health Agents in Vila Rosário, Figures 5.5–5.8 below paint a different picture. It is built by Leila, who is using herself as an example of families who can afford to buy food, to have health care, and to feed adequately.

In Figure 5.5, Leila is showing us her new terrace. She took this picture to show a view of Vila Rosário neighborhood and to illustrate a house of a middle-class family. In Figure 5.6, Leila was drawing the layout of the house to explain how they, at Vila Rosário, usually enlarge their houses. She explained that the terrace is a recent addition, which covers the house. Under the terrace, there are two rooms, one bathroom, and another room that still is being repaired. In

FIGURE 5.5
Health Agent proudly showing the landscape from her new terrace.

FIGURE 5.6
Health Agent sketch of her home's location in the neighborhood.

FIGURE 5.7
Leila's most enjoyable place at her house.

FIGURE 5.8
An empty plot next to Leila's house, to be transformed into a kitchen garden.

Figure 5.7, she shows the place she likes more in her house. It is nice to see that she is very proud of her home. In Figure 5.8, she is showing a plot of land that is by the side of her house. In this plot, there used to be a house, but the dweller left the house with his family. He claimed that he had no money to repair the house and there was too much humidity caused by the neighbors who had elevated their houses because of floods. As he has no money to do the same, his house was increasingly affected. This is a common fact in poor communities. People leave their houses to find a better place to build another, or they find a new one that has already been abandoned and move into it.

She explained that the problem was the standing water near the house, and because of it, they started to have dengue.[20] Therefore, her husband searched the old dweller and bought the house. Now her husband is filling the plot with earth to elevate it, and they plan to transform it into a kitchen garden.

SPENDING TIME WITH SOME INHABITANTS IN THEIR HOUSES

Health Agents invited us to go to their homes, to spend time with them and their families. In these visits, we could get a window into their lives. For example, we could see:

1) How the old lady of the house took care of her great-granddaughter, which helped us understand the baby-care issue;
2) What kinds of TV shows they liked and why they liked them, which led us to start an inquiry about the visual repertory of the community;
3) How family members interacted amongst themselves and with neighbors.

FIGURE 5.9
An overall view of the street

FIGURE 5.10
Garbage problems

Also, we had been snacking during the afternoon, which gave us a suitable opportunity to understand more about the community's eating habits. The participants showed us living quarters, told us stories and answered our questions. As far as we can say, they did not try to limit our access to any issue or to any member of their families. They truly allowed us to share information about their lives, and allowed us to take part in it briefly.

From the ambulatory, we went to Maria do Rosário´s house. On our way, we started to see a reality different from what we heard on Health Agents' stories. We started to visualize Vila Rosário's houses by the standards of the mainstream society. Some houses are protected by tall walls, and almost all of these had intercom systems as well as air-conditioning systems (Figure 5.9). At the same time, we could see problems of waste management (Figure 5.10). Despite this community being considered below the official poverty line, there are wide social differences in it. We could see that some people have social characteristics that could place them in many social classes at the same

20
http://en.wikipedia.org/wiki/Dengue_fever

time. For example, Deolinda´s grandsons are undergraduate students. Both work as Webmasters and Web designers, have computers at home, and are well connected to the Internet and by mobile phones. They play instruments in a rock band.

At Maria do Rosário's house, she talked to us about her attitudes, values and beliefs. In her opinion, cultural values are based on human relationships and social responsibility. As she told us, she transmits her values through stories, songs, and talking about the "old" days.

1 Seated in the backyard of our house I contemplate, the
2 pretty sunny day, the green color of the trees, the
3 birds singing, how these simple things make our life
4 better and happier. It has been 48 years since I live here;
5 there is a hill on the left side of our house: in the
6 beginning there was nothing there, but now there are
7 many trees. The landscape changed because people
8 from the countryside came to live in that hill.
9 They cultivated the land and they planted trees of:
10 mango, jambo, jack-fruit, avocado, acerola,
11 so many banana trees and other kinds of fruit trees.
12 Myself, today during the morning, sitting here praying
13 to God to say thank you, for everything the Lord gave
14 to me: my work as health assistant, is so good to take
15 part in a so beautiful (special) work. Thank you God
16 because with this work I could be useful for a time.

From her description (lines 1-4) we get a vivid image of a person who enjoys simple things she considers important to her life. For example, she described how the landscape had been changing over time (line 7), and how people used the land and cultivated things they had been growing when they were children living at the countryside (Figures 5.13–5.14). Another point about this is that there are many people from the countryside living at Vila Rosário; they had brought their values and traditions to the community (lines 8-11).

We can notice the importance of faith and religion (lines 12-13), and also the social responsibility of her work. She wants to give back to the community her sense of how to improve community life, by respecting the balance between mankind and nature (lines 14-16).

In Figure 5.11, Maria do Rosário is showing that for every child that she had, her husband had planted a new tree from seedlings. By now they have a backyard with a lovely shadow provided by virtuous trees. In Figures 5.12–5.14, she describes how the community had changed in the last 48 years. In her opinion, the values changed a lot. The youngsters were getting more selfish and not so connected to nature. For her, the family is the base to rescue the good values.

FIGURE 5.11
Everybody looking at the trees planted for children a long time ago

FIGURE 5.12
Maria do Rosário looking to the scenery and describing her memories associated with the landscape.

FIGURE 5.13
Showing the landscape and describing how it used to be in the past

FIGURE 5.14
An attentive audience for a very good story

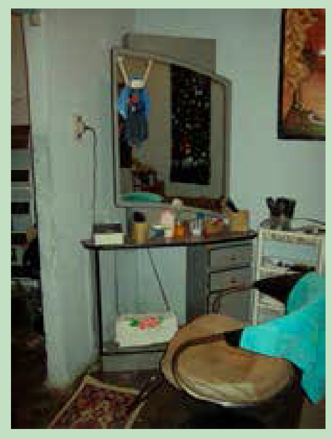

FIGURE 5.15
The researchers and the oldest Health Agents.

FIGURE 5.16
The whole family talking about the community, cultural norms and expectations about the project.

FIGURE 5.17
A hairdresser showing the entrepreneurship spirit of the family. On the mirror, there is a doll that is being sold to help and spread the work of IVR.

FIGURE 5.18
Example of a minimalistic kitchen, built with little money, but good standards of hygiene and accessories for cooking.

FIGURE 5.19
Stock of material to be distributed to people in need.

FIGURE 5.20
Deolinda (HA) showing a Bible that she received from a patient. She was describing the importance of being religious and having faith.

These moments that we spent in her house are moments not to forget. It was incredible how she was describing a whole life and what she considers important in it. She was sharing with us her knowledge about the community, but also her convictions about the importance of the relationship between people.

STORYTELLING INTERVIEWS

In a paper about storytelling as an empathic design method, Katja Battarbee details how stories work as "shortcuts to meaning." People love to tell stories using their own words, and structuring interviews around stories also provides a way to give the control of interviews to people. Writes Battarbee:

> Stories give a quick, memorable introduction into the particular issues of study, especially what people do, how they do it, and what problems they may encounter. Stories are a good starting point for more structured and detailed research. Everyday stories are usually interpreted without much attention. Stories collected from users in a design project, however, often require the team to acquire new, domain-specific knowledge. Stories are also ambiguous and people interpret them from different personal experiences and professional backgrounds. (Battarbee 2003: 109)

Stories give designers insights into how people understand themselves, their environment and their peers. They also give designers a way to see how objects, devices, technologies and other relevant things in their lives are connected to each other. A sensitive analysis of a story can open up a lot: it gives designers a window to how people organize things in their head.

To illustrate storytelling methods, we can take a look at one example. In this example, Custodia talks about Health Agents and their relationship with the inhabitants of Vila Rosário.

Custodia – file 10037.wma (03:47 – 10:37)

1 Well, I am going to tell you a story that can illustrate our
2 relationship with the population well.
3 To start to take care of this family, I had to try three
4 times before being invited to come in. In the first, two times
5 I did not receive any answer from them. Nevertheless, I
6 used not to give up easily, and I attempted again. In my third
7 try, the family decided to receive me and listen to me.
8 I have been doing a work of orientation with this family. In
9 this house, there is no tuberculosis case, but there are
10 other illnesses and other problems related to health, like
11 bad hygiene. They have kids, and I really am worried
12 when there are children involved in the picture. Kids are
13 more vulnerable and they are going to be our future.
14 First, I am going to explain the house landscape: it is a
15 little hill were the "man" built four houses, one for
16 him, his new wife (Maria) and their kids; and the other
17 three houses for the daughters he had with his first wife.
18 In their yard, they had animals like ducks, goats,
19 pigs, hens. It has a farm of animals. Nevertheless, there is
20 no special place for the animals. They run free in the yard,
21 and they can even enter into Maria's house. Maria does not
22 have good hygiene in the house because of the animals. She is
23 not worried about this issue. The other three houses are very
24 clean. Once I asked the other women (stepdaughters) to help
25 Maria regarding to hygiene but they told that they do not
26 spend much time at home (they have a full day work), and
27 they do not speak with Maria. They have a tough
28 relationship.
29 Well, coming back to Maria's daughter story, the little
30 girl, Carol, almost had to amputate a hurt leg, because of a

31 small boil (furuncle) in her toe that was growing
32 and became a serious infection. I know that people with poor
33 hygiene or malnutrition are more susceptible to getting
34 furuncles. In addition, in Maria's house they lack both
35 nutrition and hygiene. I told Maria to take Carol to the
36 doctor, as she was already having fever. However, she said
37 that she could not go to Caxias by herself because she is
38 not able to locate herself there and she gets lost.
39 Therefore, I decided to go with them. I know that she knows
40 how to move around Caxias very well. Nevertheless, I know
41 also that she is the kind of person that loves to ask help
42 from other people, loves to say that she is not able to do the
43 things just to receive help and not have responsibilities.
44 This kind of situation happens here in Vila Rosário,
45 and as Health Agents and citizens that want to improve
46 our situation, we need to give this kind of support to
47 people.
48 As soon as we arrived at the Health Center in Caxias
49 for the appointment, Dr Alexandre said to me: "You again?"
50 He told this like a joke, because as Health Agents, we used to
51 go to the Health Center to manage many issues related to our
52 community, like trying to book appointments, to accompany
53 some patients, and so forth. I answered to him: "Oh my God,
54 it is me again, doctor!". In this moment, he looked at Carol
55 and said: "We need to keep this little girl here for
56 treatment." However, Maria did not want to hospitalize
57 Carol. Dr Alexandre asked me about the girl's situation at
58 home, and I talked about the lack of hygiene, so he decided
59 to insist with Maria to leave Carol at the hospital. He
60 was worried about the situation; if Carol did not receive
61 the right treatment, the damage could become severe.
62 But Maria did not allow Dr Alexandre to hospitalize Carol. He
63 asked her to sign a disclaimer. Doctor Alexander prescribed
64 antibiotics, explained how to treat Carol and highlighted
65 the importance of the hygiene and nutrition.
66 As I know Maria very well, I decided to take care of Carol.
67 However, unfortunately, I was not able to stay full time
68 with Carol, so, I asked one of Maria's stepdaughters to take
69 care of her, and she accepted. Do you believe that Maria
70 decided to bring Carol to her house during the night!!
71 (Custodia, talking, to us, in a very angry voice!)
72 Therefore, the situation of Carol's foot got worse, the
73 infection spread to her leg, and this innocent child almost
74 had her leg amputated because of bad hygiene!"

From Custodia's story, we can catch many important points to understand the community behavior and habits related to health issues, and to the Health Agents work. Custodia emphasized that it is not easy to be invited to the houses, or even to be listened by people (lines 3-7).

Even more important to us was that we could see that even though the Health Agents' work is connected to tuberculosis and other tropical illnesses, they also needed to take care of hygiene related issues (lines 8-11). Also, we saw that an important group to focus on are children. This was an observation that was confirmed to us by specialists and once more, by Custodia (line 11). In Vila Rosário it is common to find situations where families share the land, or even the house. It is common to avoid new expenses. Above, for example, the stepmother is sharing the same land with her husband's daughters (lines 14-17). Another problem is that people in Vila Rosário raise animals but do not have space for them. In some house, animals are even allowed to stay indoors (lines 18-21).

Just as hygiene, nutrition was another important issue to be considered. During our interviews in Vila Rosário, we were given examples of cognitive deficits that were caused by malnutrition, which had many detrimental consequences to social and economical well-being. This is the case in the community, as in the whole country (lines 32-36).

Another point identified by Custodia is that many people at Vila Rosário community wanted to be dependent of others' help. They say that they prefer to receive aid rather take initiative in taking care of their responsibilities by themselves (lines 39-44). But it is not only because people avoid their duties that the Health Agents need to accompany someone to a hospital, for example. Usually the Health Agents need to go with their patients to the health center just to give emotional support.

This is another responsibility that is not prescribed in their job description, but nevertheless is something they think is important (lines 44-49). Some people from the community do not trust the public health system; they prefer to come back to their homes. We identified this during interviews and during probes as well (lines 56, 67).

It is a normal procedure to ask people from the community to sign a formal acceptance of responsibility for their acts. In the case above, the doctor asked the mother to sign a disclaimer not to have problems later if the kid gets worse (line 63).

However Custodia did not accept Maria's decision and argued with her, she knows that the kid is not responsible for the mother's acts. So, Custodia decided to take care of the kid (lines 66-71). Maria is a young woman, and she came from the poorest of families. She is reserved and can sometimes be aggressive. In Custodia's opinion, Maria is afraid of her new situation at her husband's family (lines 23, 28). These are examples of Health Agents' indispensable local knowledge.

FACES AND VIEWS OF VILA ROSÁRIO FROM THE HEALTH AGENTS' PERSPECTIVE: HEALTH AGENTS ASKED TO TAKE MORE PHOTOS

After Health Agents started to trust us, we organized another interview. This interview was different from the initial one in that it was collective. It was also based on photographs we had asked them to take for us with the disposable cameras we had given them. In this interview, they put the photos on the table and talked about why they took these photos. They built many kinds of stories with the photos. For example, they not only took photographs of the main entrance of a house, but also of its other spaces, until they reached the end of the backyard.

Custodia:

1 If you want to have a deeper understanding about our situation,
2 give us more disposable cameras. One for each agent is not
3 enough. The situation is difficult, the houses are
4 precarious, we have many things to show to you.

Stories like these were invaluable to us in our effort as they helped us to visualize the stories Health Agents told us. For example, in the next story, Custodia describes us a local man who has many types of problems with his health.

The dweller lives alone (Figures 5.21–5.22); he is a victim of intracerebral haemorrhage (ICH), and because of his physical condition, his neighbors help him to clean and organize the house. The Health Agent wanted to show us the necessity of appropriate technology and means of cleaning and organizing a house for disabled people. For example, in this bathroom, there is no running water and no equipment to help him during his bath. The friends have minimized the risk of accidents by placing a plastic chair in the "shower booth" space. According to the dweller, this simple improvisation makes easier for him to shower.

The family has issues with hygiene, largely due to the problem of basic sanitation and inadequate housing (Figures 5.21–5.23). By paying attention to the image, it is possible to see that the door is not fixed to the wall; the hole in the wall is smaller than the door. The Health Agent explained that the dweller had found this door in a garbage and just added it to the wall. This is the reason it has no glass and does not fit. These problems are very common at Vila Rosário because of the lack of education and income. Most of the household income goes to the husband's alcohol addiction. This is the reason the focus of Vila Rosário´s program focused on empowering women rather than men.

Figures 5.24–5.25 show two cases of family routines. The Health Agent took these pictures to show us a family meeting that takes place during the weekend. She wanted to show us

FIGURE 5.21
The bathroom of a patient

FIGURE 5.22
The patient

FIGURE 5.23
Patient's kitchen

FIGURES 5.24–5.25
Family routines

that the community, despite its dire situation, is very connected, and its inhabitants greatly respect family life. With these two pictures, Health Agents illustrated different living rooms of different families. Despite their different economical level and family organization, both are examples of families that care about basic issues in life.

However, these two pictures tell very different stories. The photo on the left side was taken to show us a family organized according to the values of the mainstream society. The photo on the right shows a different form of family. It illustrates a family of single mother, 48 years old, which has been suffering from tuberculosis and diabetes. The Health Agent wanted to show the lunch time of this poor family that lives in a one room house. Even though she is poor, the woman tries to decorate the house and keep everything clean and organized. Through this picture we discussed the nutritional balance of the families, but also its daily habits like watching television.

Another theme Health Agents raised through photographs was the connection of lifestyle and poverty to hygiene and health. The Health Agents took some pictures to build this link in a more concrete way, and explained the scenario to Marcelo and I with

other Health Agents. In the following two pictures the Health Agent highlighted the fact that the animals are free; there is no appropriate space to place them. The animals are also free to go inside the house. Another point was the inappropriate way of dressing the child. The child is barefoot in a place with animal excrements (Figure 5.26). The Health Agents pointed that this is a common sight at the community. Figure 5.27 shows that with no sewer system, the inhabitants relied on septic tanks, often improperly built. When it rains, the garbage and the dirty water enter the home.

FIGURE 5.26
Children playing in the yard, with feet unprotected

FIGURE 5.27
Improper septic tank

FIGURE 5.28
Possible patient with multiple problems

Six persons live in this house (Figure 5.28). The man at the "door" is alcoholic and he has a mental disorder. He also coughs a lot, so he may have tuberculosis, but the Health Agents do not know this yet. They plan to do the diagnosis during their next visit. They told us that in this first contact, they were just trying to understand the situation, and make the family trust their work. They shared their experience with other Health Agents and the specialist doctor, to gain a better understanding about the situation. Based on the discussions, they will choose what kind of approach might best improve this family situation.

The man in Figure 5.28 lives in the house with his two daughters, his wife, another two persons, and a dog. One of these people is a tenant; he rents a piece of the house, which in fact is the only part of the house that has a small, improvised roof. Health Agents told us you can hardly call this a house. From their point of view, the family lives as if they were homeless people, but in a yard with fences. The house has no roof. There are just three walls. There is no floor either. It is just a brick structure.

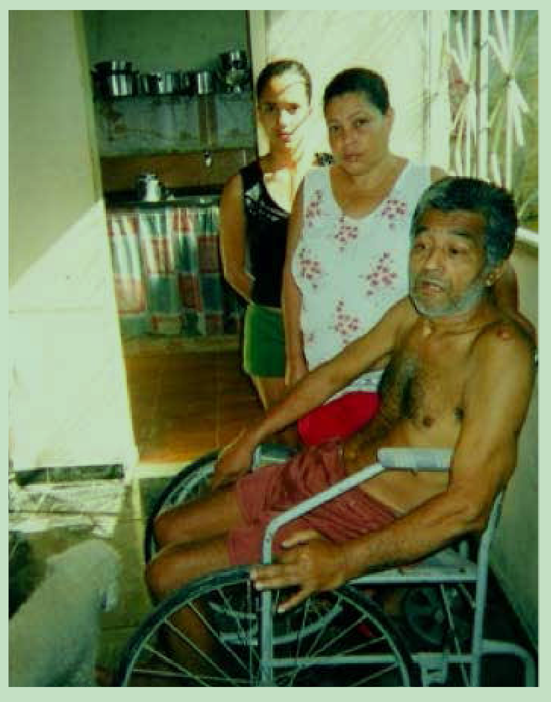

FIGURE 5.29
Another patient with multiple problems

FIGURE 5.30
A family with multiple problems

When you look inside, you can see mattresses dropped on the ground and plastic bags with clothes inside.

The man in Figure 5.29 was a victim of intracerebral hemorrhage. The family was economically better off than average, but could not afford a wheel chair, so the Health Agents had mobilized the community so they could have the chair for him. They told that the funniest thing is that the chair is not particularly strong so, as soon as the Health Agents tried to put the man sitting on it, it broke. Because of his physical condition, the man cannot sit on his own. He has to throw his body on the chair, so the Health Agents fixed the chair, and did an improvised design to make it stronger and more suitable for him. Now the chair is working well.

The couple in Figure 5.30 are alcoholics. They did not have a permanent job, and the woman had tuberculosis. The Health Agents were following up her treatment. The Health Agents told us that when they asked permission to take the pictures, the couple dressed up and tried to organize the house. The couple told that photos are like a social event. The house had one room only; there was a structure in which they planned to build a bathroom, but they did not have it yet as there was no running water. The couple washed their clothes and the dishes outside on the yard. The woman told the Health Agents that she bought the washbasin to be more hygienic. With loudspeakers collected from the garbage, they listen to the music they love very loud, and as they do not have official electric power at their home, they did an illegal connection to have it.

The Health Agents told us that during the treatment of the woman, they had to face a different situation. When a bus run over her, her neighbors contacted the Health Agents to accompany the woman to the hospital. As soon as Deolinda (the Health Agent responsible for the case) arrived at the house, she

saw that she was wearing her only dress. Because of the accident, however, it was damaged. Deolinda contacted other Health Agents, and they collected some clothes for her. The neighbors told us another interesting fact about this family. They said the couple always goes to the church, and they love to speak at the microphone during the ceremonies.

FIGURES 5.31–5.32
Living in unsafe houses

What can be seen based on the pictures in Figures 5.31–5.32 is precarious housing. Living in houses like these is not safe. There is no basic sanitation in these houses, and the inhabitants do now have an understanding about the importance of sanitation. All the children have verminosis (parasitic worms) and scabies. They were already being treated, but because of poor hygiene, they had contracted these parasites again. These are houses with no sanitation nor bathroom. The inhabitants bathe in the yard, close to the pigs and other animals. Their excrements were everywhere around the houses.

Stories like these led Health Agents to another recurrent theme. Figure 5.33 illustrates domestic garbage and other discarded materials thrown away in waste grounds. Some inhabitants from Vila Rosário had to be educated about the importance of proper garbage treatment. If the garbage truck does not stop in front of their houses in the time they are awake,

Health Agents told us they simply throw away the garbage in any place, and also inside of their own houses and yards. There had been cases of people who know that the garbage trucks schedule is 7:30 am, but they wake up at 8:00, and as they do not want to wake up earlier, they stock the garbage at home or throw it away on an unused plot of land.

FIGURE 5.33
Illegal dump

FIGURE 5.34
Locally organized garbage collection site

This is not the whole picture, though. There is the example of one inhabitant who had been organizing the garbage management on his street. The man lives on a street in where the garbage truck does not have access (Figure 5.34). It is not asphalted and has hundreds of potholes. Facing the situation the man organized a place into which residents could place their garbage. In the place, there was a sign with the schedule of the garbage truck and the places where the garbage truck has access. He also managed to organize other residents from the street to do the garbage collecting work in turns.

Another problem is infrastructure. An open sewer follows one of the main streets from its beginning to its end, and then turns and follows the other street as well (Figures 5.35-5.36). The name of this neighborhood is Parque Nova Esperança (New Hope Park)

and the streets are called Rua da Paz (Peace Street) and Rua Beira Rio (Riverside Street). Health Agents told us that they wonder if these streets have the proper names. There is no river: it is an open canal carrying raw sewage. There is no peace on the street as the people, especially kids, and older people are often ill. During raining days and the rainy season the streets become a cesspit of dirty water, and the smell is often foul. Inhabitants walk through rainwater or puddles, or stand in open-air sewer barefoot or using inappropriate shoes, and are at the risk of contracting a variety of diseases and infections associated with bad sanitation and poor building practices, including cholera.

FIGURE 5.35
Open sewers

FIGURE 5.36
Open sewers next to houses

FIGURE 5.37
Abandoned buildings attract rats and insects

Waste grounds and deteriorated buildings or abandoned constructions (Figure 5.37) are places where insects and rats collect, making these places favorable breeding grounds for many contagious tropical diseases. Another problem, as Health Agents repeatedly stressed to us, is the habit of inhabitants to throw away the garbage in places like these.

SIGNS OF HOPE

Despite all the poverty and its consequences, the community is filled with enthusiastic and spirited inhabitants. The children cannot afford to buy toys but they are happy playing at the community field with self-made toys. People in Vila Rosário sometimes walk on their bare feet and they do not always dress adequately, but there is always a lovely smile on their faces. They may be invisible to society, but at the same time people are so talkative and have so much to tell (Figure 5.38).

FIGURE 5.38
Happy faces in Vila Rosário

The following two pictures were chosen by the Health Agents to exemplify the business opportunities people find at Vila Rosário.

Figure 5.39 is a picture of a hairdressing salon (it is the same we have seen earlier in this chapter). This picture was taken by Marcelo and I. When we showed it to Health Agents and asked them to talk about the photo, they made many interesting observations about the photo. They told us that this photo is important to them as an example of how people can find opportunities to reintegrate in the workforce. In their opinion, we took the photo having the same thought in mind. The owner of the hair salon decided to open her own business when she perceived that women at Vila Rosário like to improve their style,

their appearance, and that they were looking for a place to do so. Another point Health Agents made was that the locals like to go to the salon to talk with other people. They used the space to ask opinions about how to dress to go to a party; to talk about their own life; to gossip; to read magazines; and so forth. The salon is not only a place to get a haircut, but it is also a place for a cup of coffee, and for passing time.

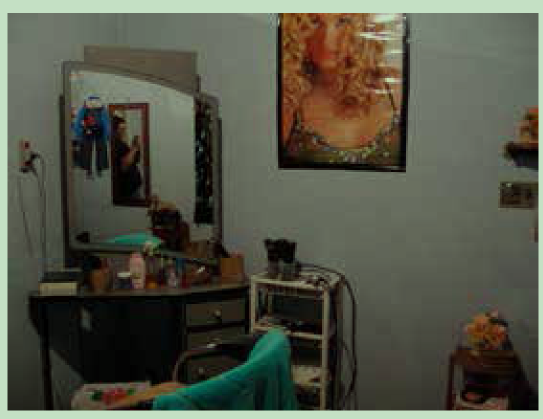

FIGURE 5.39
Entrepreneurs: local hairdresser salon

FIGURE 5.40
Mr. Manuel's candy cart

The owner of the salon also uses the space as a "window" to show the products that people are developing at Vila Rosário Institute. The owner found in the salon space a good opportunity to disseminate the ideas of Vila Rosário's project. Moreover, the Health Agents have stressed that this family had a very good sense of business opportunities; the two sons of the salon's owner often invited their friends to listen to music. As the boys had a band, the neighbors and their friends liked to go to the boys' house for entertainment. After this went on for a while,

the family saw a good business opportunity in it. They saw that people from the community needed and liked this kind of entertainment; in addition they noticed that people like to have some beverage and snacks during the time they spend watching shows. Now, the family is designing a space in the backyard for auditions, and they are also designing a snack bar.

In Figure 5.40 is Mr. Manuel. He was 85 years and had stomach cancer. He was the owner of a candy cart. He needed to have the cart to earn money because his pension was not enough to pay his rent of 78,00€/month and his medical expenses of 25,00€/month. He also needed to have money for food. Summing up his pension and the money he received selling the candies he earned, he was able to make about 115,00€ per month. Because of his cancer he was not able to work every day, however. Sometimes he felt himself too tired or he had so much pain that he preferred to stay at home to get some rest. He did not complain about his work as a carter; quite the opposite: he was happy and grateful that he had an opportunity to earn money to sustain himself. He was also happy because his work allowed him to interact with other people, and especially with children. In his opinion, it was always wonderful to be with kids: they are always happy, telling stories, using their creativity, and dreaming of better in their imagination. In Health Agents' opinion, Mr. Manuel was a good example of entrepreneurship; moreover, he was an example of courage and determination.

In Figure 5.41 are two women who helped Custodia to take the photos. Custodia told they were her collaborators; she pointed out that her friends, even though they were not officially part of the project team, were always happy to help her. This was a very interesting example of the importance of the connections among community members and their desire and disposition to improve the community's situation.

FIGURE 5.41
Health Agent Custodia's helpers

The Health Agents told Marcelo and me that in their opinion, the Vila Rosário Institute Project (former QTROP project) has already improved the life conditions of many inhabitants, but people involved in the project still had much work ahead. For example, to fight tuberculosis, Health Agents had to expand their task quite a bit: they had to educate people to change several habits that may lead to the disease. Inhabitants need to change their focus from people who need to receive everything for free, to people that fight to reach a self-sustainable community. Inhabitants also need to change their attitudes. Often, they accuse other people fot their own mistakes, instead of learning from those mistakes. If inhabitants focus their attention on finding scapegoats, they will not go forward with their own lives. What Vila Rosário needed was self-confidence.

6

Health Agents and Technology: Access, Attitudes, and Dreams

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in Fieldwork

In this chapter, I will focus on technology in Health Agents' work. First, I will describe the first contact Health Agents had with a data base developed by Dr. Claudio Costa Neto. Second, I will explain the main characteristics of the software and then proceed to other technologies. Third, I will describe two initial studies we conducted with projective techniques in Vila Rosário. These studies were aimed at freeing Health Agents' technological imagination from the bind of their everyday reality.

VILA ROSÁRIO DATA BASE

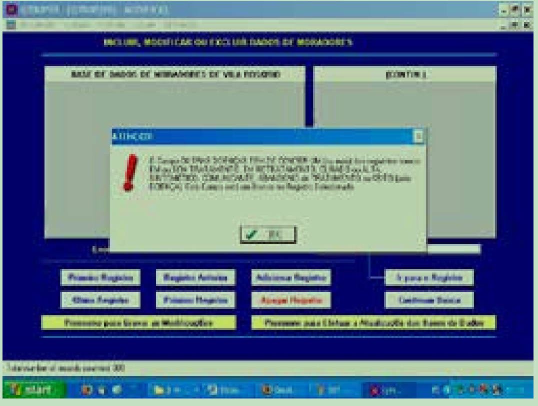
For the participating doctors, Vila Rosário project was more than *pro bono* work. It was also a research project. To assist

data collection, it has a data base, which had been developed by Dr. Costa Neto. The main aim of the data base was to function as information repository, but it was also aimed at improving communication between Health Agents and specialists involved in Vila Rosário Project. It was dynamic. For Dr. Costa Neto, it gave him a centralized access to data collected during the project. It was developed to be easy to add, to consult, and edit information.

For instance, it was designed to make it possible for many sorts of specialists to do searches and instantly have access to data from Vila Rosário. Dr. Costa Neto had categorized these data by patient, address, street, age, profession, and illness, among other things. These different kinds of categorizations helped the specialists to do searches based on their needs.

FIGURE 6.1
Dr. Costa Neto training the
Community Health Agents

FIGURES 6.2–6.3
Print Screens of the database
developed by Dr. Costa Neto



For example, to a nutritionist, age is an important factor to be considered. A doctor interested in diarrheic illnesses can search cases by address to understand the environmental conditions. Once a specialist had access to this database, she could access data related to illness like tuberculosis, hepatitis, HIV, and syphilis. Through her knowledge, she could plan and take strategic decisions contributing to improve the future of the community as a whole.

Dr. Costa Neto also trained Health Agents to entry data into the database. During a presentation of the software to Health Agents, he was describing an example of tuberculosis case to explain how the database helps him in his work. For example, he explained how by starting from a specific tuberculosis patient, he can build a hypothesis on how the disease can change the whole community. When the Health Agent is on the field, she can start to fill paper forms that will be later transferred to the database. By transferring the essential information to the system, the data is updated weekly. All people involved in the project had access to the database and could filter information according to their needs. For Dr. Costa Neto, the database will make the project more dynamic.

Health Agents agreed with Dr. Costa Neto that the software was a necessity in improving the process of information. Transferring patients' data from the paper forms to the digital database helped the Health Agents to organize the data efficiently. It helped them to prioritize the update and gave them a reason for filling all the fields of their data entry forms. These fields were organized to allow specialists outside Vila Rosário to build scenarios for guiding new strategies to fight the illnesses found. Some of these strategies were indirect. For instance, if the specialists saw that in the some street there was a cluster of families with poor nutrition, they can devise a plan to solve

this issue. Or, if they see that there is a cluster of illiteracy, they can organize reading classes. At the end, all the efforts would improve the quality of life and reduce levels of illness.

Considering that people in Vila Rosário came from many Brazilian regions, it was important to understand from where they came from. Depending on their origin, it was possible to create new policies to try to combat and avoid the spread of diseases. Dr. Costa Neto highlighted that it was very important to actively monitor the spread of illnesses. If the data is not accurate, it can mislead doctors, and as consequence, the treatment could not be done in the best possible way. Dr. Costa Neto had reminded the Health Agents that the information should be collected carefully.

In particular, this was important for people with tuberculosis. Once the treatment starts, it leads to a significant improvement in the patient's condition in the first fifteen days. Some patients start to think that they are already cured and stop to take the medication, thus ceasing the treatment. If the treatment, however, does not last at least 6 months, the patient is not cured. Having data in the system, the team could identify which patients leave the treatment during this period, and could follow these patients closer to make sure they continue the medication. Dr. Costa Neto told that the worst case scenario is a person who needs to start the treatment again. The treatment had started to kill the weak bacillus, while the survival bacillus gets stronger. It could be a threat to the community because it can create a super-bacillus resistant to medication.

At the end of Dr. Costa Neto's demonstration, the Health Agents were very happy to have the software, as they recognized that the software will help them in their work, especially in regard to filling the paper forms. They told to us that even though the paper forms were done based on their needs (Dr. Costa Neto had developed the forms with them), it is very stressful to fill

all the fields while visiting the patients. They had developed a strategy of writing their observations into a notebook first, and filling the forms with the data they have written in the notebook afterwards. The form was used as a guideline to remind the Health Agents to ask the main information about the patient and her life. The Health Agents have learned that it was important to collect and write or record as much information as possible to achieve their long-term goal of improving the patients' life. Data collection would help them to understand how to proceed during the treatment.

Based on what they told us, we saw that they had collected many kinds of information from each case, and the forms functioned just as a guideline to remind them about general information. However, their field observations captured in the forms contained very important information related to individual patients. Some Health Agents were not confident that the software would improve their work, and hinted to us that they were afraid of using the computer. Dr. Costa Neto told them that they will get training to learn how to use it, and the course will be a part of their training as Health Agents. Another point he emphasized was that in the beginning, they would have a person to help them to update the database; he would be there as well.

HEALTH AGENTS AND INFORMATION TECHNOLOGIES

To get a rough idea of how Health Agents use the database, and also how they use other information technologies, we wanted to first evaluate how Health Agents could use the database.

In order to understand the Health Agents´ level of interaction with the software and with computers, we scheduled usability tests which, however, had to be canceled. We modified the approach: we decided to inquire the Health Agents about their

relationship with technology instead of doing usability tests merely. After Health Agents had finished training with Dr. Costa Neto (it was their first day of training), we could easily notice the different levels of expertise among them. On one hand, Leila had her own notebook; she has also a mobile phone; and she felt very confident with new technologies. On the other hand, Marluce seemed very shy and uncomfortable with the situation when she was in training. Faced with this situation, we asked the Health Agents to come in pairs to the computers room with us "to have a chat." As they were considering us a part of the Institute team, there was no resistance. Health Agents continued their conversation while coming into the room when Custodia and Marluce came in. The other Health Agents stayed with Dr. Costa Neto to talk to him about their reports.

The first thing Marcelo and I did was to start chat with Custodia and Marluce about their work and life. We started to talk about issues related to nutrition, and then went on to a discussion about the training workshops, and to how the community could be reintegrated into the workforce. During this chat, we placed the video camera and the recorder properly. The chat also worked as relaxation after computer training. As soon as the layout was organized, we started the inquiry: Marcelo changed the subject from nutrition to technology.

Our first questions were about mobile phones. Marcelo asked Custodia and Marluce if they had mobile phones. They gave us a straight no and said nothing more, just waiting for the next question. Feeling their anxiety about new technology, Marcelo and I decided to ask the women to tell stories about people interacting with phones and computers. After the change of the interview approach, conversation started to flow. Our role also changed from a researcher to a friend. For example, Marcelo and I started to talk about our difficulties in using an

ATM in Helsinki due to the fact that the interface is in Finnish. We asked Custodia and Marluce if they use an Automated Teller Machine - ATM. Marluce told that she has had difficulties to use the ATM because she is not fast enough to enter the data: before she can enter it, her card is already blocked. After having the card blocked, she needs to go to the bank and ask to unblock it. To unblock the card has proved more troublesome than going straight to the cashier and asking her to check her credit.

Another point Marluce underlined was that she always felt insecure in the ATM queue. In her opinion, a person using the ATM needs to pay more attention at people who are around. She told that it is very common for people who want to rob passwords or cards to be around, just to observe the clients. The robbers also check who is at the ATM to make withdrawals. According to Marluce, sometimes a bank teller comes to help. Usually, this happens when the queues are long. Even then, she prefers to go to the cashier instead. Custodia agreed with Marluce and adds something Marluce forgot to tell: the cashiers have instructions to send the client to the self-service ATM, not to help them to use it. Custodia told us that this is a matter of having a personal relationship with the cashier. When the cashier knows someone and knows her difficulties, she is willing to help her. If the cashier is new to the customer, the latter needs to go to the ATM, or come back another day.

For Custodia, the process of using the ATM is nerve-racking. She explained that for her, it had been difficult to first remember her six number password and insert these, and then to remember her two-letter password. She knew that the screens give instructions about how to proceed, but the time to change from one screen to another is very short and she has no time to read the instructions. She thought that there are so many steps to do the transaction that it is a fatiguing process. She also told that

the ATMs are not designed for short people; she is 1.44 meters tall and cannot see the screen in a proper position. She also thought that the screen is dull and the fonts are too small. Marluce agreed with her: she is also short (1,45m), and even though she wears glasses, she has difficulties seeing the screen of the ATM.

As the atmosphere in the room was very relaxed, Marcelo changed the subject from ATM to computers. He asked from Custodia and Marluce whether they had ever used computers? As both of them were very relaxed, Custodia answered that she thinks computers are very important artifacts to have, especially for research and for interacting with people around the world. She told that her niece always does her homework school with a computer and finds all subjects she needs from the Web. In Custodia's opinion, it would be hard to find information about many issues from TV, radio, or even the library. She said that is especially hard to find information at the community library because of its small collection. She told that her nephew is a teacher and has promised to teach her how to use a computer. She seemed to be very enthusiastic about the idea. It was a good opportunity to ask her if she would use the bank services by computer. She mentioned that while being at home, or in a private space like the room in the ambulatory, she would not have the time pressure to do the bank transactions.

1 Of course I will use it! On a computer I will not have that
2 people shouting: go faster madam! ... Will you finish today or
3 tomorrow? ... People in line don't care if you are nervous
4 about the situation... In my computer I can have my time! And it
5 will be more secure. I know that you can access the bank 24
6 hours a day by computer, right? So I would choose the time my kids
7 are sleeping and do everything calm and quiet.

I have written on the same subject with Marcelo in a paper published in 2005 (Judice and Judice, 2005). In our paper, we found that many users of ATMs have the same reservations

Custodia and Marluce had about ATMs. Our study was about 12 middle school students from Brasilia. All of them had personal computers. The majority told that they fetl comfortable to use ATMs and computers. However, when Marcelo and I went deeper in the tests, they saw that when with a personal computer, they could do transactions without the stress of being in the queue. Just as Custodia and Marluce, these students stressed that in front of an ATM people, it is easy to get embarrassed if you are not fast enough with the procedure. If people are not confident about what they should do, they are afraid of losing money or making mistakes, and for this reason, they give up the transaction. The majority of these students did not feel comfortable enough to ask for help because they did not feel safe on the streets.

After talking about ATMs, Marcelo and I decided to go back to mobile phones. We asked them if they had ever had a mobile phone. This time Marluce answered. She said she had a mobile phone a long time before. She told it was one of the bigger models, big as a brick, and she only used it to call and to receive calls. She stressed that, in her opinion, a mobile phone is so different from landlines that she was afraid of using one.

Custodia also said that she had a mobile phone in 2000. It was a basic model, easy to use. She told us that the mobile was easy to use because it had few functions, while nowadays mobile phones have games, cameras, etc., that make them a lot more difficult to use. Then Marluce expressed her opinion: it is important not to give up the idea of using mobile phones. For us, this was interesting, as she had earlier told us that she was afraid of using mobiles. She also said that the most important thing is to keep training. She said she believes that just as with computers, you need to practice every day with a mobile phone.

Marcelo asked both women if they thought it was important to have a mobile phone. Custodia explained she does not have

enough money to afford one. She stressed that for her it is important to have a mobile phone, but she will only buy one when she can afford a sophisticated device with games, photos, movies, mp3, and other things. She empathically said that she does not want to have a basic model. So, we asked her why she needs more functions on her mobile phone than what the basic phones have to offer. Her argument was that she needs it to do her work. She told that as they have hard cases to take care, sometimes they have difficulties to approach a patient who is really ill. When they approach the patient, they need to record and to take pictures to prove that the situation is difficult.

Marluce embraced Custodia's opinion. She told us that in her point of view one of the most important points to be considered in our design is that the Health Agents are people from the community. As the inhabitants from Vila Rosário, their families face problems similar to those we had identified in the community at large. To open up her life to us, she needs a camera more than a mobile phone. The camera can catch important moments of her lives. For example, her husband is an alcoholic; when she goes to work, he stays at home drinking. Recently, he had bought a large knife and cut the energy wire of their son's house. Then he had climbed up to the roof and stayed there until Marluce arrived. She has affirmed that if she had a camera, in that moment, she could file a case at the police office to prove her husband that the family is telling the truth about his situation. He does not believe in their stories when he wakes up in his bed, and does not remember about the incidents.

In this moment Custodia glanced at her watch, Marcelo then asked her if she uses all its functions. She answered that she uses that watch just to check the time. The only time she tried to interact with it she did a mess, and she had to call her nine-year old daughter to fix it.

INTERACTION ANALYSIS OF COMPUTER USE

Next I will describe the Interaction Analysis (IA) method used in investigating how human beings interact with artifacts in a social setting (see Jordan and Henderson, 1995). The goal of the method is to identify "patterns" during a social action, by observing how people act and interact with objects and other people while being busy in a complex social and "real" world. The only way to gather detailed enough data is to record video, which allows a close analysis later. At the same time, videos make it possible to repeat sequences of interaction countless times, and these data can also be shared with many viewers. It is easy to have these videos recorded and stored indefinitely for further analyses.

An important point to emphasize in Interaction Analysis is the Video Review Session, when the participants from the recorded interactions are invited to view the tape with the research team. When they are included, they may contribute their insights, and also point out problems in the researchers' initial analyses. Often, this is more productive than returning to the field for additional data collection. Two points to be considered carefully are: according to Jordan and Henderson (1995), researchers should use the best transcription conventions for their particular purpose; their other point is that Interaction Analysis is time consuming. The project has to be very well planned to complete all steps and have good results.

Heath and Luff (2000) note that the dominant approach for analyzing what people do with computers in a research field called Human Computer Interaction (HCI) typically builds on cognitive science, and tends to adopt experimental method by default. Analysis focuses on measures like the time people need to react to events on the screen, or how long the users spend

in doing a predefined task. These are normally compared to some idealized model of the activity. For example, one of these models comes from information processing psychology that examines how much information humans can process in some situation. The problem with these analyses is that they usually forget to analyze interactions between users and artifacts in a real environment, and they also neglect the social origin of these interactions:

> HCI and Cognitive Science diminish the importance of the immediate context of action, and in particular, the ways in which plans and schemes have to be applied and defeased with regard to the contingence with emerge during the execution of practical actions and she shows how the meaning of plans, scripts, rules and the like, is dependent upon the circumstances in which they are invoked; they do not so much determine conduct, but harder provide a resource through which individuals organize their on conduct and interpret the conduct of others.
> (Heath and Luff, 2000:10-11)

To get an idea of how the Vila Rosário project database was used in a real setting, we conducted a study of a training session at the ambulatory. The transcription on the next paragraphs is an example to understand the way we did the interaction analysis in Vila Rosário. It is not a complex situation, but real in the sense that it was modelled after the training sessions of Dr. Costa Neto. For us, interaction analysis provided an access to verbal and non-verbal data during use. With this interview, we could understand better how stressful the real situation of using computers is for Health Agents.

Participants to the session were Marcelo Judice and Custodia. I stayed in the background.

FIGURE 6.4
The ambient layout of the scene

(20:00)
C: Custodia; M: Marcelo Judice; A: Andre Judice

1	M	do you know what this icon means?
2		{stands up pointing at the icon}
3	C	{looking the screen for >7 sec, holding her chin}*a
4		letter?* It is a folder
5		{approaching the computer screen}
6		Doesn't it look like a folder?
7		{C leans against the back of her chair, and turns
8		gaze towards M}
9		(2.0) {anxiously waiting an answer}
10		It is like an archive folder.
11		{C gesticulates impatiently, as
12		having a folder in hands; getting the body
13		straight on chair}
14	M	It looks like a folder. (1.0) So, what do you think
15		there is inside it? {M turns his gaze towards C}
16	C	*I think it is my personal data* (2.0) I think it is my
17		personal data. /MY PERSONAL DATA.
18		{C leans against the back of her chair}
19		That is [my data, isn't it?] It means personal
20	M	[it is written "My"]
21		(2.0)
22	M	So, this is your computer.
23	C	{smiling}
24	C	=[probably is relating to myself]
25	M	[What procedures you need to do to open this folder?]
26		((C. didn't understand the question, probably because
27		C. was speaking at the same time as M.))
28	C	(1.0) {C. stops to talk and look to the
29		computer screen.
30	C	=[{C turns her gaze towards M}

Figure 6.5
Marluce and Custodia explaining what they expect for the session.

Figure 6.6
Custodia looking suspiciously to the computer monitor.

Figure 6.7
Custodia explaining what she can understand from the icons.

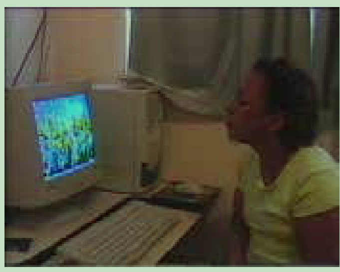


Figure 6.8
Custodia analysing the interface.

Figure 6.9
Custodia experiencing the mouse.

Figure 6.10
Custodia analysing the computer keyboard.

31 C [Hum?]
32 M How can you open this folder to have access to the
33 documents that are inside it?
34 C (5.0) {looking the computer screen}
35 C I need to take it and move it
36 {showing and taking the mouse}
37 Ai! {C. gazes towards M having an interrogative
38 expression on her face}
39 M What happened?
40 C The Arrow moves forward
41 {Holding her chin, looking the screen
42 for >5 sec. and hesitates in approaching the mouse
43 again}
44 C It is the starting point, am I right?
45 A {laughing quietly}
46 C {gaze towards M and A}
47 Guys I am lost! {laughing and moving
48 her body at the chair}
49 M =[You should not feel lost]
50 C [I've never been in front of a computer before!]
51 M Do not worry, there is no problem. I will not let
52 you to make mistakes. We are here to support you.
53 C {apparently more calm, shaking her head positively,
54 gazes towards the computer}
55 C Then, I will move upwards
56 C (2.0)
57 C this arrow. Isn't it? (---)

((15 minutes of interaction))

58 C {smiling, analyzing the computer screen, with a more confident
59 attitude}
60 A {smiling and standing the thumbs up to encourage C}
61 It is just a training issue. We need to practice every day.

From the transcription, it is possible to see some gestures and emotions that stressed a few aspects of the situation better than interviews. In particular, we see that for Custodia, using computers is a new experience, as line 49 shows. Also, many features of the interface were unfamiliar to her, including basic features like some of the key icons (lines 1-23), using the mouse (lines 34-39), and how icons function (lines 31-37). She also

had to stop many times to think about what was going on (for example, long pauses in lines 3, 33, and 41).

As a whole, this episode and many others showed us that Health Agents were unfamiliar with computers and their interfaces, and their level of understanding their basic elements were minimal. They were also quite uneasy about using and just clicking things on the screen. On the other hand, they learned fast by clicking icons and reading them. The experience did not prove out to be difficult; the system was learnable, given some support in using the system. This was important information for us in the early stages of the study; these features of use would have been difficult to observe without videotapes and our fairly detailed transcripts. Time for usability experiments came later.

PROJECTIVE METHODS IN FIELDWORK

In our ethnography, we also used many kinds of projective methods familiar from design literature. These methods aimed at freeing people's imagination by giving our research a playful character. The methods have been advocated by the *Presence Project* – Gaver (1999, 2001), but also Sanders and Dandavate, (1999) who stress that there are some things people do without really thinking about what they are doing. They find it difficult to talk about these things. Observing these things would take much more time than we usually have in design. To Sanders and Dandavate,

> "An adequate understanding of user experience requires three types of methods: verbal data ("Say": what people know and tell), behavioral data ("Do": seeing and observing what people do), and data on emotions and dreams ("Make": the use of non-verbal, constructive means to describe and represent experiences)... New tools must focus on what people make—how they construct their world for themselves in their dreams, imaginations and ruminations of various sorts... The ability to not just know, but

also to empathize with the user comes only at the deeper levels of their expression. By accessing people's feelings, dreams and imaginations, we can establish resonance with them. Special tools are needed to access the deeper levels of user expression."

We used two types of projective techniques in our study to get from what exists to what could be, Good Fairy Stories and Magic Things. Judging by the amused reactions of doctors at Vila Rosário, trained in the sciences, our methods were artistic enough to tickle the imagination of Health Agents.

How would a Good Fairy help Health Agents?

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. Once more, I am using Custodia as an example of the results we have had.

62 ´You know, when I was in Maria's house, the same family that
63 I told you the story about, I would like to have
64 a home cleaning kit with me, to teach her how to clean her house.
65 I also wanted to have a photo album, so I could show her that
66 these photos are showing the reality of her house, the house
67 she lives with her family, and if she does not help me to
68 clean it and keep it clean the situation is going to be
69 worse!
70 In this album, I want to have photos from her house and
71 photos from another family - like Maria's family and a house
72 like her house too - but the family living in a clean house,
73 all of them healthy and happy. Maybe, with this album I can
74 find a motivation for her to clean her house and keep it
75 clean!!

76 In her house, there are many illnesses: Leptospirosis,
77 cholera, most of the time the kids are vomiting and with
78 diarrhea.
79 Once I went to Maria's house, to do my routine visit, and I
80 had to cut Carol's hair. I was there, and I saw the girl
81 crying, so I decided to pay attention to her, and I saw some
82 small insects flying around her head. I thought they were
83 flies. So I caught the girl and I went to Maria's
84 stepdaughter yard, it is impossible to stay in Maria's yard
85 it is so dirty! When I look at Carol's hair in a careful way,
86 it was full of lice! Her head was completely scarred. In
87 moments like this, I can say that I feel myself so impotent.
88 We want to improve the community life! We are doing some
89 stuff to improve the situation; we go to people's house, we
90 follow up the treatments, we help to clean houses, we help
91 to afford food, and so forth, but if we don't go for one day in
92 their houses, when we come back the situation is worse,
93 or they relapse to their old habits.

As we see, Custodia felt herself very confident in telling us the story, and gave us many tips that helped us to develop suitable products for situations she was describing. She chose to tell us the story of Maria again. Based on her choice, we could see that despite Vila Rosário Institute program having its focus on tuberculosis, we had to reach out attempts beyond this disease. In Maria's case, nobody is ill with tuberculosis, but there are other issues as poor hygiene and the lack of information about health, and so forth, that are of equal importance to tuberculosis, and complex enough to warrant attention on their own.

Earlier, Custodia spoke about the necessity to compare a bad scenario with a good scenario. At the end of her Good Fairy Story, she showed the person how the Fairy could help Maria make the choices that would lead to many positives changes in her life. For Custodia, a dramatic intervention is needed to motivate people to change their habits. If the approach is too smooth, people usually stay with their habits and do not make the effort to improve their situation (lines 9-12). Finally, we can

identify more diseases that Health Agents need to deal with in her description, like cholera, Weil's disease and diarrhea (lines 15-17). Custodia's Good Fairy will be very busy at Vila Rosário.

Magic Things in fieldwork: Imagining new technologies

Magic Things are mock-ups that represent a magic mobile device that would function much like the Good Fairy in Health Agents' stories (Iacucci et al. 2000). It is a simple physical representation of a device so smart that it would solve all kinds of problems in Vila Rosário, as if it had magic powers. Magic Things are purposely almost without qualities on their own, which basically turns them into 3D projective versions of classic ink blot tests. With very little meaning on their own, they tickle the imagination to turn it into an observable form. The difference from psychological tests is that Magic Things are situated and focused on functional qualities of information technology; they are not personality tests administered in an office.

The Magic Thing worked well for us because it is a tool applied without specific focus, imposes no boundaries and no restrictions and allows the unexpected. With it, we asked Health Agents to explore their needs, wishes and beliefs in their actual life. I created a context in which technological ideas are elicited and understood in real life, without researchers controlling the situation. They also free imagination from stereotypical formats like mobile phones and "apps". The user managing the situation is not passive or shy; she can feel comfortable in context as she is in control, and the context is familiar from her own life. She allows herself to dream and to show researchers what the community needs. She also lets them to take part in her own world. Two other interesting points to be highlighted are: the low cost for developing the Magic Thing, and, as it has no predefined

functions and shapes, it helps users to deal with it and allow users to point concepts and functions of products based on their own experience. Therefore, it fills the gaps between current experience and future use (Iacucci, Kuutti, and Ranta 2000; Hagen, Robertson, Kan, and Sadler, 2005). Magic Things were applied as yet another step in deepening our understanding of Villa Rosário, its local culture and its daily life.

To apply Magic Things, we were monitoring the activities of community Health Agents during one working day. The activities were recorded on a diary and on maps to understand their mobility. Also, we took photographs, recorded video, and conducted semi-structured interviews in combination with the Magic Thing. The aim was to register all kinds of facts and to observe what happened when Health Agents were doing their work. The method highlighted many interesting aspects of the situation. As designers, we had a well-structured idea of which factors are contributing to the problems faced by the community, but we did not understand in detail how Health Agents encounter things like inadequate sanitation and poor nutrition. At this point of the study, the main question was: what types of products and services would meet the needs of this community (Margolin & Margolin, 2002).

During their working day, the Health Agents carried the Magic Thing. It was used as a portable device that could help them in situations and provide solutions to specific problems and situations, including problems that required third parties like the intervention of doctors or hospitalization. From an in-depth understanding gained during our earlier analyses, we came up with a relatively simple and open-end design for the Magic Thing.

When passing in front of the two houses with the researchers, one of the community agents stopped and began to describe the

following situation. As Clara, one of the Health Agents, explains, sometimes she hopes she would like to contact TV networks in her work to catch attention for the people at Vila Rosário.

Using the Magic Thing as an assistant to contact people from TV.
Clara 10037. Wma 10:50 begins

1 The other day one lady came to complain with me: "my
2 'daughter', this is the 'septic-tank' (fossa) of my
3 neighbor, when she flushes the toilet it fills my yard with
4 dirty water (wastewater). I am getting crazy with this
5 situation. I do not know what to do anymore! I am afraid of
6 getting hepatitis; I have my children and have to be
7 careful. My 'daughter', says to me what can I do to prevent
8 illnesses in a situation like that?"
9 In that moment I had no answer to that woman, I felt
10 depressed!
11 I told her: "Madam, did you already ask orientation about it
12 in the city hall?" and she answered to me: "Yes, I did. But
13 they said they can make nothing to help me!"
14 The street where she lives is half asphalted. It is
15 asphalted in the beginning and in the end, but not in the
16 middle of the street. For me, that land was a swamp and
17 they just added sand on it and started to build their houses
18 over it. This woman has a two month baby of, a little four year-old
19 girl, a six year-old boy of and a little boy with one year and
20 ten months. In these day her kids and some friends, around
21 five kids, were playing in her yard.
22 Because of this lack of basic sanitation, this street has
23 much illness, as Leprosy (Hansen's disease), hepatitis, and
24 others. I already took care of two people with tuberculosis,
25 three with leprosy and some with hepatitis. Moreover, we,
26 Health Agents and community members, we know that the
27 biggest problem is in the lack of basic sanitation. Walking
28 by the street you can be astonished by the amount of
29 mosquitos, I am quite sure that you can find the mosquito
30 responsible for transmitting dengue fever to humans there.
31 Another day, I even found a snake there.
32 Of Course, this situation is extremely unhealthy, especially
33 for kids. I would like to have more aid from other
34 institutions, or other agencies, to change this scenario.
35 So if I had this Magic Thing in that moment, when the lady
36 came to ask what to do facing that situation, I would

37 take my Magic Thing and I would like that it showed to me
38 which people can help me to change this situation. I wanted
39 to press a button from my Magic Thing and it brings to me
40 people from the television, or it can put me in contact with
41 those people that I can explain them our situation to
42 sensitize them, if they could see our place, I am sure they
43 could understand our situation. In addition, those people
44 could do an interview to show our situation. I believe that
45 with this interview someone important is going to watch it
46 and will come to help us.

Applying the Magic Thing method allowed us to have many insights about the situation of the community. Understanding the mobility of agents was not restricted to geography/physical mobility and navigation, or to the way agents accessed and transmitted information. The Thing also gave us access to how the agents would have wanted to use technology, and what capabilities they would like to have on a mobile device. It also gave us access to different types of communication/ community in Vila Rosário, and how these communications were organized and how they occurred in social activities of the village. The Magic Thing reinforced some of our observations, but it also brought about new insights into the habits of that social group, its local culture, its behaviors, its beliefs, and their interconnections.

During the Magic Thing study, it became clear to us that access to information and the mode of application of the method must be negotiated and agreed in advance with all parties involved. Direct observation with photo cameras and video and even the annotation can generate constraints; they can modify behavior and even turn participants away. Thus, there should be an agreement that would regulate the balance between the privacy of the participants and the needs of the researchers. In our study, there was no problem as long as we were working in the community, as we had gained the trust of Health Agents.

Researchers knew when they could or not use all the instruments of research, because they understood a lot about local rules and the culture of the community. Such knowledge cannot always be assumed, though.

As we had envisioned when designing the study, Magic Things quickly showed that solutions of low technological complexity were more appropriate to community members. However, it also showed that to some stakeholders like doctors in town, it is essential to use sophisticated communications technologies.

7

Concept Design: From Users to Design Program

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What kinds of Information Systems are going to be useful and enjoyable among Health Agents working in Vila Rosário? In our studies so far, we could perceive that Health Agents are key persons for effective interaction among people living in Vila Rosário, and so are doctors, nurses, specialists, volunteers, nuns, and so forth. In this chapter I will focus on how we translated our understanding of health care in Vila Rosário into concept designs that prepared actual design work.

The design language I developed with Marcelo Judice is explained in his thesis in detail (M. Judice 2014). Therefore, I will only give a rough description of our design approach. The approach built on Pelle Ehn's classic book on participatory

design *Work-Oriented Design of Computer Artifacts* (1988a). One research line in this work consisted of Ehn's attempt to ground his design effort in Ludwig Wittgenstein's later philosophy. What Ehn learnt from Wittgenstein was the importance of situating any design effort into the form of life of a community. Designs have to communicate in the language games of the form of life of this community. The form of life consists of a massive set of background knowledge against which people make sense of things they see. Things that they cannot make sense of are misunderstood or irrelevant. For us, the most important design implication of this notion was that we needed to design for the community by identifying and understanding its language games. The difficulty is that any picture or word – or any design – is determined by its use, and this use is thoroughly contextual:

> "The aspects of things that are most important to us are hidden because of their simplicity and familiarity. (One is unable to notice something - because it is always before one's eyes.) The foundations of this enquiry do not strike man at all. Unless that has some time struck him. - And this means: we fail to be struck by what, once seen, is most striking and most powerful."
> (Ehn 1988b: 144)

What Ehn taught us was that we needed to pay attention to the massive social and cultural background if we wanted to create designs that were understandable in Vila Rosário. To do this, we had to understand the form of life in the community (Wittgenstein 2009/1953: #23). The most important thing was to understand its language games, and how designs take meaning in these language games. There is no way to know what they are and how many are there (Wittgenstein 2009/1953: #7, #23). We had to learn to know the community to be able to design using its vernacular.

THEMES ADDRESSED WITH DESIGNS

The first task was to identify a set of themes, as Freire put it in his *Pedagogy of the Oppressed* (Freire 2005: 114-115). From the probes and our fieldwork in Vila Rosário, we identified five main themes that could be addressed through design: how to help Health Agents in diagnosis; how to help them to communicate with doctors; how to help persuade patients to take medication; the importance of hygiene; and proper nutrition. These were the issues that came through again and again, first in the probes study, and through various studies during our fieldwork.

1 Helping in diagnosis

The challenge the Health Agents underlined most frequently happen during the time they visit a person or a family to identify if the person is ill and what kind of illness the person was taken by. The Health Agents faced four main steps in their work:

- Identification of the ill person and disease diagnostic;
- Guiding the patient to treatment;
- Giving an explanation about the illness to the patient and the family;
- Doing a follow-up of the treatment.

These problems happen because of many factors like: the Health Agents do not have training to identify all kinds of diseases, and they cannot differentiate between many kinds of diseases. Some diseases practically speaking have similar symptoms to others. Sometimes the patient feels herself reluctant to discuss her situation. Sometimes they omit facts that would be important for the right diagnosis, and so forth.

To change or to improve this situation Marcelo and I started to develop concept designs. The aim was to use the concept idea as a tool to support the development of healthier Vila Rosário.

The main challenge became how to improve the diagnoses. To do so, we need to improve communication among doctors, Health Agents and patients.

2 How to improve communication with doctors

During the interviews and the Magic Thing study, Health Agents underlined their need to talk to the doctors more often, especially when they are doing diagnoses. They said even if they have a landline as well as a mobile phone, and can use e-mail to talk to doctors, they do not find these efficient enough for their work. Sometimes they have no credit to call; sometimes the battery of the mobile is down, when they go to the patients houses it is not common to find a land line; some of the houses have no energy; some Health Agents do not have mobile phones; and the doctors are not free to help every time Health Agents need help. Occasionally communication with the patients can be difficult because they are afraid of having a disease that stigmatizes them, or they mistakenly think there is no cure. The Health Agents told that it is very common to arrive at a house to visit some possible patients and people say: "Don't be alarmed, I just have a common flu. People are overreacting! Come next week and you will see, I will be ok!"

For these reasons, Health Agents want something to share images and other data with doctors. They said that sometimes, they are visiting patients and they have doubts about the symptoms. If they have a video to show how the patient is behaving, or a photo to send to the doctors, it could help them a lot (after listening to these wishes, we asked them about their mobile phones). In brief, they need something that can connect them to the doctors straight away. They told us that

they know they can send messages by mobile, but they think that the doctors can be too lazy to answer, or cannot recognize the number and do not answer the call. They wanted something that is more efficient in this kind of interaction.

Regarding the patients, they wanted to have some kind of device that can show a video, pictures, booklet, or other kinds of material that can help them to show the symptoms and the treatment to the potential patient.[21] This would help Health Agents in their effort to be taken seriously by people in Vila Rosário. Once more, we asked about mobile phones, but it seems that they have little knowledge about how mobile phones function. Also, they highlighted problems with batteries and credits, and they were also worried about the small screen that would make it hard to show the information to the patients convincingly.

3 How to help persuade patients to pay attention to the symptoms of disease and to take medication

Another problem was related to patients and how they can be persuaded to recognize symptoms. Doubts on diagnosis can have consequences like: postponing the beginning of the treatment; the illness can get worse; the patient can leave or never enter treatment (this is very common in Vila Rosário), and so forth.

4 Hygiene

Hygiene was a problem of particular importance for tuberculosis and diarrhea, the most common dangerous diseases in Vila Rosário. Specifically, there was little appreciation of the importance of hygiene among children and young mothers. We developed several designs to address this concern.

5 Nutrition

The final theme that was identified in fieldwork was nutrition. As doctors told us, there are many myths about food in Vila Rosário, and as they are poor, their diet tends to have lots of energy and it fills the stomach. However, it may be poor in terms of essentials like vitamins, minerals, and fibers.

DESIGN DRIVERS: MERGING LO- AND HI-TECH

Following Freire and Ehn, we wanted to create a joint language game with members of the community (see Marcelo Judice's doctoral thesis, M. Judice 2014). Our designs built on those local resources that people in Vila Rosário use to organize their own understanding. All our visible designs had to build on the vernacular of the local culture, its look and feel. They had to be made familiar and desirable for children and adults alike.

The key distinction for designing for Vila Rosário became one between hi-tech and lo-tech designs. The distinction came to be made in workshops and design

21 At this moment, they told us that the booklet we planned to develop to improve their work would actually work. It was nice to hear from them that they are sure they need a booklet to help the work.

TABLE 7.1 THE MAIN AUDIENCES OF LO-TECH AND HI-TECH DESIGNS	Lo-tech designs	Hi-tech designs
	Children, teens and women: designing familiar characters, stories, comics, games for learning health care information; *Health Agents*: designs structuring Health Agents' observations and advice, gathering records for doctors.	In contrast to lo-tech designs, hi-tech designs were mainly targeted at Health Agents and medical specialists in Vila Rosário.

critiques in Helsinki, and also in a series of papers explaining the fieldwork (Judice & Judice 2007, 2009) (Judice, Judice & Garrossini 2013). The main bulk of designs became lo-tech: easy and cheap to produce locally, and having little value as such, to make sure there is no incentive to steal them.

For two reasons, despite our original brief, IT came to play a secondary role in the design: the absence of proper infrastructure, and safety. Electricity and data connections in Vila Rosário were not reliable, and valuable objects like computers were too attractive for thieves. We decided to place IT into the Vila Rosário Institute, where it was safe and where people knew how to use it. The main users were Health Agents and nuns at the Vila Rosário Institute. For them, IT became a means to building a bridge between the Vila Rosário Institute and medical expertise in the metropolitan area.

TABLE 7.2
DESIGN PRODUCTS
BY THEMES AND
BY AUDIENCES

Themes	Diagnosis
	Communication
	Persuasion
	Hygiene
	Nutrition
Audiences	Health Agents
	Doctors
	Other specialists
	Senior citizens
	Adults
	Teenagers
	Children

Thus, we created a Web-based communication system between Vila Rosário and doctors in local universities and clinics.

Needless to say, the definition of "hi-tech" depends on context. In Vila Rosário, using existing communication infrastructure and building on the Web was hi-tech, as it involved using electronic communication formats with which Health Agents were not always familiar.

DESIGN PRODUCT MATRIX

The following matrix lists the final designs. The designs are described in next chapter and also in Marcelo Judice's doctoral thesis (M. Judice 2014). The matrix also shows which problems we wanted to address through our designs, and which was the main intended audience of each design.

Lo-tech designs				Hi-tech designs		Visual identity	
Booklets	*Posters*	*Games*	*Workshops*	*Portal*	*Educational movies*	*IVR design management program*	*Health Agents' kit*
+	+	+	+	+	+		
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FICTIONAL VILA ROSÁRIO: DESIGNING THE SKIN

After settling the main design drivers around the theme of lo- and hi-tech, and selecting a few local language games for building the actual design, the next question was how to design the actual products so that they were understandable. Several choices were available. We rejected artistic and commercial styles, as they were alien to both Vila Rosário and the seriousness required by our topic, health. We also rejected medical style, i.e. typical medical design stressing white colors, simple, clean surfaces, and scientific shapes that communicate technical sophistication and reliability. These would have been out of place in Vila Rosário, given poverty on its streets and its tropical landscape.

Instead, we decided to build local character into our designs, picking up symbols that were important for local people. These symbols included things like local flowers, bright tropical colors locals prefer, popular TV soap operas, and local characters in all their richness. Therefore, the final designs became a collage of the design drivers as enriched by things local population understood and found important. In the spirit of design for hope, the idea was to create designs that would easily make sense.

The actual method we used to manage this task was building a Fictional Vila Rosário and using this fictional village as a reference in creating designs. This world became a reference point we came back to in doing more detailed designs for our products.

To simplify the design effort and to make designs consistent, we created a story world. In the center of the world were characters that were created with a *telenovela* style, for several reasons. Everyone in Vila Rosário understands these characters. They are simultaneously stereotypical and detailed, easy to identify with, but not too close to any particular person. Furthermore, their

behaviors and their impact on other people can be followed over time, which makes it easy to communicate things like how some behaviors lead to certain outcomes (like getting a TB diagnosis followed by a cure, and finally getting better) and how these behaviors affect other people (like what happens to the loved ones if one does not take care of TB properly, or stops the treatment early) (Figure 7.1).

FIGURE 7.1
Examples of characters in the fictive Rosário

These storytelling resources were important in recreating Vila Rosário in designs. It goes without saying that all decisions concerning design elements were based on the probes and the ethnography done earlier. Once the world had been created, designs were easy to produce quickly. Material for all designs came from probes and fieldwork. The main benefit of the story world was that it made it easy to communicate health related information. It helped to translate abstract medical information into something stories could be made of.

TOOLS FOR DEFINING DETAIL DESIGNS

All these themes were built using the local knowledge we had gained with our probes and our early fieldwork in Vila Rosário. The aim was to create a series of stories that would help us to keep Vila Rosário vivid in our eyes throughout the design process. In defining the final design program, we translated these themes into designs using standard interaction design tools of personas (Cooper 1999) and scenarios (Carroll 1995).

TABLE 7.3
CHECKLIST IN PERSONAL CREATION IN VILA ROSÁRIO

Who were the intended audiences?
Researcher / Doctor; Front-office Doctor; Nuns (social service, nurses, etc.); Volunteers (teachers, project managers, etc.); Health Agents; People from the community (2 families – 4 generations); Nutritionist.
Social aspects of personas
Group of personas: children, pre-teenagers, teenagers, young adults, young parents, adults, elders, grandparents, grand grandparents. The model became Monica de Souza's family: they represent a family of 4 generations.

Personas

Persona is a description of an archetypical user, synthesized from a series of interviews with real people. Each persona provides goals that drive product design strategies. If we focus on each persona's goals, we can develop a product that satisfies the needs of many users. The main questions followed to develop the personas were: What is persona's main aim? What problems are personas supposed to solve?

Most important needs and goals of our audience

Claudio (chemistry)
1) Archive: story of the project: photos, records, interviews, scientific and non-scientific papers, reports, projects related to wellbeing (illness prevention, job, education, etc). Evaluations and results. 2) He wants to have a connection between the databases (with information from Vila Rosário) on the website.

The variation in capability between the different personas

The influence of lifestyle and life stages on product use; the aspirations of each persona, and hence the motivations to achieve different tasks with different products;

Content

Name; Age; Photo; Personal info (family and life at home); Work environment (tools, work conditions, task flow); Expertise level (skills to work; to use web; to use computer); Technical frustrations (technological conflicts); Technical motivations. Scenarios and/or stories about users (give him/her name, a background, a task to accomplish on the site – task from our list of users, needs and wishes – write a story and create the scenario about how the character uses the webpage to complete the given task).

Use of technology

What kinds of experiences related to technology do they have? Why will they come to visit the webpage? The importance of each audience to the portal to be designed? Why will they come back?

In our approach, we intend to develop personas not only to focus on high technology, but also lo-tech designs. As we perceived, the lo-tech is also extremely important to the efficiency of Vila Rosário project. For a great part of the residents of Vila Rosário, lo-tech products are more suitable for their realities. How to integrate our personas into the design process as a whole? Not only through the webpage.

We wanted to focus on what the persona would get out of using a well-designed product or service. Our first task was to identify behavior patterns; goals, environments and attitudes; in this first step we built this information without adding any personality. Our second task was adjusting personal details: for example, what our persona does after work, or what kind of personal touches he/her adds to her workspace? The third task was adding more local character to the personas, so we asked a series of questions. How the persona wants to feel when using a product, for example, having fun, and not feeling stupid? This is an experience goal. Want to feel confident that the transactions are secure? The final task was to customize visual design: selecting experience relevant to the local community (colors, fonts, and other visual elements) by asking questions like "Do we feel comfortable and secure using a site that is orange and purple, uses funky type", or "Would navy blue and a crispy simple font be a better choice"?

After defining how the personas were to be construed, we analyzed the position of each persona within a family and social network and defined in detail what the personas were doing.

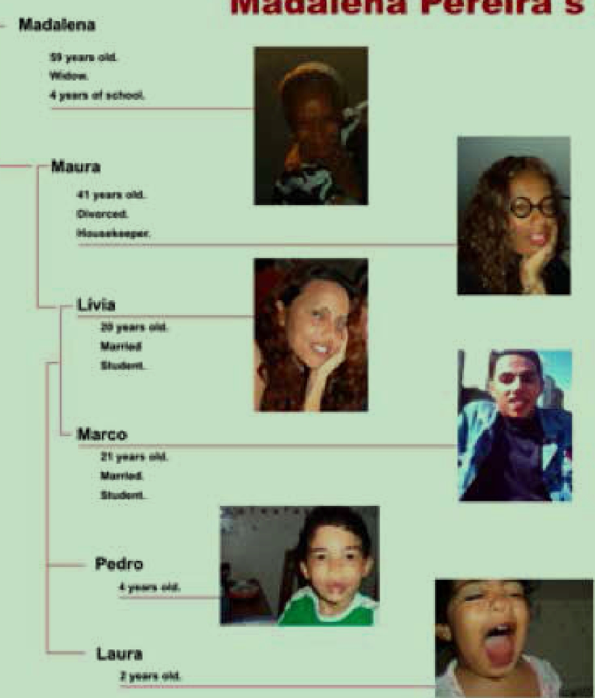
1) Person, business and family;
2) A day in their life: following the persona on a typical day;
3) Work activities: job description, role at work;
4) Household and leisure's activities: what the persona does when he/she is not at work;

5) Goals, fears, aspirations (life and career);
6) Computer skills, knowledge and abilities;
7) Technology attributes (what he/she does with technology);
8) Attitudes to technology (perspective on technology, past and future);
9) Communication and interaction habits (how the persona keeps in touch with people);
10) Quotes from interviews and observations.

When building personas, we analyzed people's stories to see how their daily life went on. For example, we analyzed the day-to-day activities of one doctor when building a persona.

6:30	He wakes up; He does his morning routine: takes his breakfast with his son and wife; reads a paper; checks and answers some emails (some wait, some are rushed, some deleted)
8:00	He leaves home; He goes to a Pilates class. He enjoys this moment and uses it to relax and interact with different people with different backgrounds.
9:00	Goes to Fiocruz (a hospital in Rio de Janeiro, ipec.fiocruz.br). Even though he has lots of phone calls to do, he does not like to use his mobile phone while is driving.
9:30	He arrives at Fiocruz and checks his to-do list for the morning using his desktop computer.
12:00	He has lunch at Fiocruz, withdraws some cash at the ATM.
12:40	He leaves the hospital to drive to Vila Rosário.
13:10	He arrives at Vila Rosário.
15:00	He goes to Casa de Apoio.
17:00	He goes home and has a walk to pick up his son at the school. Before dinner, they catch up.
18:00	Dinner time! Yummy! The family likes to eat having Mozart as background music.
19:00	TV time: he sits on the sofa, to watch some movies to relax with his family.
20:00	Back to work. He uses a broadband connection to have a video conference with his partners around the world.

Madalena Pereira´s Family



Madalena lives in Vila Rosaria since 1958; she saw the community growing fast and in a non-optimistic way during the last years. Since the year she moved on, she start to be "in love" with that place, she told that every tree that we can see in her yard she cultivated with her husband.

She is a volunteer in Vilas Rosario's project. She said that she is very happy to work with something that can improve the community's life situation.

She is a very optimistic, positive and flexible person.

She thinks technology is a very important tool to help to improve the community's life, but she never felt herself confident to use it! "Once I tried to use my daughter's mobile phone, but I did a mess and I even couldn't answer it (laughs)"

She lives in a small house: 2 rooms, 1 living room, kitchen and 1 bathroom.

In the same house live:
Her daughter **Maura** – has a high school diploma
Her granddaughter **Livia** - student / unemployed
Livia's husband **Marco** – unemployed – he dropped the school when he was 11 years old and he never had any other kind of formal education.
Her grand grandchildren **Laura** and **Pedro**, both are not in the school yet. The queue is really huge.

Maura works as a maid in a family's house in Copacabana – a medium class neighborhood.

Nilza Almeida

Female.

40 years old.

Married.

2 kids

Teacher at public schools / Volunteer at Vila Rosarios' Project

She is graduated in Art-Education

"Working as a volunteer within a very different context is a huge challenge and, although hard at times, is very rewarding and pleasant. The attitude and the behavior of the community's members and their desire to learn and to improve their lives are inspirational".

During her time at Universidade Federal do Rio de Janeiro - Fundão she was involved in teaching and supervising practical classes, this background is helping her a lot with her new job as volunteer. She told that she really enjoyed her first taste of being a real teacher. She remembered when she came to the community for the first time: "I was so excited and at the same time so afraid. I came from a complete different context and i grew up listened lots of stereotypes about slum community's and the people that live there. When I saw every body sitting in their chairs waiting for me, all of them with a big smile in their faces and with lots of hopes and expectations about my class I felt myself the luckiest person in the world!"

Nilza always was engaged in social and political causes. She is very worried about her conduct as a citizen from a developing country, she really thinks about her rights and her duties as a Brazilian Citizen.

"I really want to do something to change our situation. I want to contribute with my skills to improve some communities. Some persons are saying to me that what i am doing is so small that nothing is going to change! But I believe that with small things we can change a lot ... it is a beginning for something bigger."

Nilza become teacher in this project, after Sister Maria identifies the necessity to start a course of Stained glass (vitral) to the community. She told that the most challenging things in her new job are: teaching and planning the lessons with very limited resources; most of her students are semi-literates or illiterates; and it is really hard to reach the community place.

She is trying to develop visual material to help her in classes, but she is not secure about how to develop it and if those materials are going to help. She wishes she could have help of professionals to developing it in the right way. The first time she tried to do it by herself the results were not so good. She based the visual metaphors in her visual repertory, and she forgot that most of the students never saw the majority of the visual element she used ... she was very disappointed with herself. Especially, because when something like this happen the students fell themselves as they failed in something important. As art-educator Nilza knows that they are not "guilt". And she did a dynamic with the group to try to change the situation and discover that they want to produce the material with her ... they think that sharing their knowledge and experiences they can develop appropriated material to them!

Nilza is worried about how to make the students engaged in the class. She is thinking about it because she only teaches on Wednesdays. So she wanted to have a space were she can add new material and new assignments to the students. She is thinking about a data base ... but she is worried about students skills to deal with new technologies and how they can access it.

FIGURES 7.2–7.3
A final persona

Figures 7.2 and 7.3 give an example of a persona and her network. These personas became points we consulted in detail design work, but equally importantly, they were used in workshops in which we discussed our design problems.

Scenarios

To better define what kinds of designs we needed to prepare, we built a scenario of a Health Agent at work. By inspecting this scenario, we identified which points cause difficulties, but are also important enough in her work to warrant a design. The following story serves as an example of our scenario technique.

"MARIA"

Maria is a Health Agent at Vila Rosário. Today she woke up full of energy to solve a challenge of Mr. Jose Barbosa. He does not want to ask medical support, even though something that relatives told makes Maria think he has tuberculosis in an advanced stage.

Maria searches her VR helper, which will help her to find the address of the Barbosa family. The Barbosas live in a part of Vila Rosário that is outside the official maps, but using satellite images Maria can find the right place. Once confirmed the address, she can draw over the satellite image, add the new street and upload these data on official maps. While she is using the VR helper, it is charging its batteries using solar cells.

As soon as Maria arrives in front of the shanty house, she claps her hands and a member of the family promptly replies and invites her to enter.

She is introduced to Mr. Jose. He seems pallid and ill. He is very thin and coughing a lot. As soon he sees Maria he says: "Don't worry I just have a regular flu!" Familiar with this type of behavior, Maria explains to Mr. Jose that she can help him to recover from the flu. She says that he will feel better and stronger. She starts to give emotional support to him and his family, telling stories about other people from the community that have had the same symptoms and nowadays are healthy and happy, having a normal life. Mr. Jose begins to trust Maria and starts to tell about his life

to her. She asks Mr. Jose's authorization to record the inquiry and tells about the VR Institute and Health Agents' work. Mr. Jose readily authorizes. She uses her personal assistant to record the visit. She presses a button. The screen is touch-sensitive and starts to speak: "Health Agent: Maria Aparecida da Silva, June 1st 2007, Patient Mr. José Barbosa, date of birth: April 4th 1944, place of birth: Fortaleza, Ceará." Then she starts to ask diagnostic questions.

After the diagnostic conversation, Maria is still unsure about the diagnosis. She decides to take photos, especially from some skin spots of Mr. José, and starts to record a text to be sent as a message to Dr. Pedro, doctor from the Health Center. She chooses the photo of Dr. Pedro from the screen, and presses the button to send the message.

Dr. Pedro receives the message from Maria in his personal assistant and looks at the photos. He sees immediately that the case is advanced and decides to forward the message to a research doctor. The research doctor calls him back immediately, and they start a conference call with Maria. They decide which medical tests Maria needs to request from the patient. They also select one picture of Mr. Jose, and add some comments to Maria. They send the picture to Maria with the comments.

Maria thanks the doctors and drops the conference. She presses the button to contact the Health Center appointment desk and checks which schedule is suitable to Mr. Jose.

As requested by the doctors, Maria takes more pictures of the patient and records a video clip showing the family's house. In the video, Mr. Jose and his wife talk about their food habits, and their hygienic practices.

As soon as Maria finishes compiling the video and the audio, the files are uploaded to the VR Institute server. The files will be available for further research.

Maria's next step is to explain to the family about the illness, its consequences, and the importance of following the treatment. From her personal assistant, she selects a button to access material from the VR Institute that explains the illness. She projects the content onto a wall, and she says that she can answer other questions related to health issues.

The family is thankful to Maria. They book a time and a place to meet Maria. They want her to accompany Mr. José in his

appointment. Maria takes her personal assistant to print a memo-paper with the appointment date, time and address and gives to the family.

The coordinator of VR Institute has access to the report and to the activity of the agent. She immediately sees that the case requires urgent action. Using the system by the Web, he analyses the photos and the audio-video. Based on these materials, he orders more attention to Mr Jose and his family.

After the results of Mr. Jose's medical tests confirm that he has tuberculosis and HIV, the doctor, using his personal assistant, makes a mark on the satellite map of his house. He chooses the colors representing these two diseases to make the marks. He does a zoom to get a global vision about the spread of these illnesses in Mr. Jose's neighborhood. He also updates the files about his case.

After checking with doctors and Health Agents whether this scenario was realistic, we sat down to develop a series of designs that targeted specific problems Health Agents faced in their work. Even though the scenario was technologically unrealistic at the time we were doing our ethnography, it helped us to identify several tools we could use to address the five issues we have identified earlier in our study.

STORYBOARD OF USER EXPERIENCE: THE EXAMPLE OF A TABLET

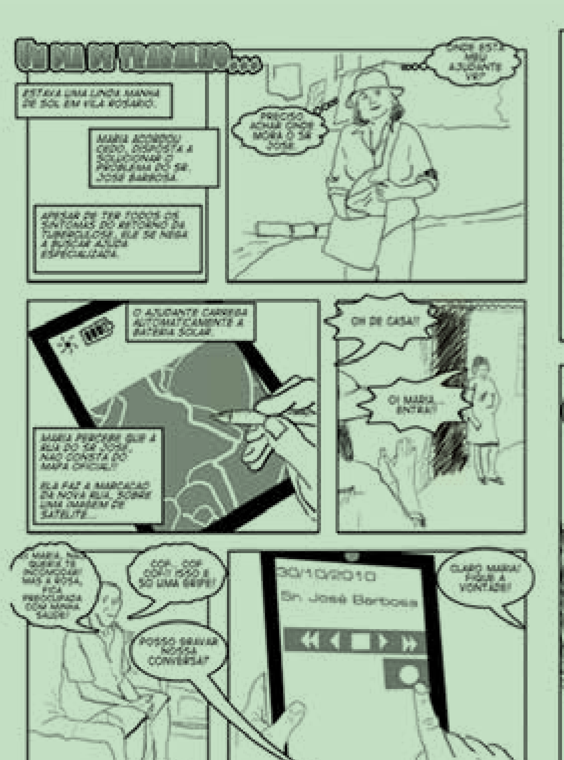
Finally, we developed a series of storyboards to illustrate how the designs would work before entering the actual design work. These storyboards were drawn in a comic format to give them a local flavor. They always described a story, a visit to the patient, how some piece of design was supposed to help in their work, and how the design helped in communicating information to doctors, if such communication was needed. They also showed how various elements of the program worked together.

CONCEPT DESIGN

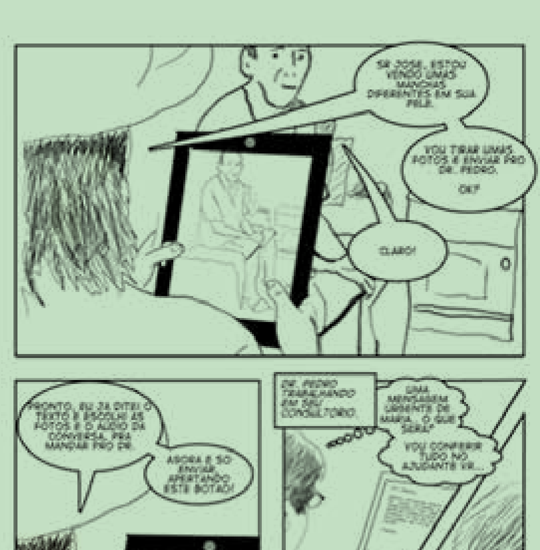
As Figure 7.4 shows, we could also add (then) non-existing technologies in our storyboards.

FIGURE 7.4
Storyboard of a tablet application

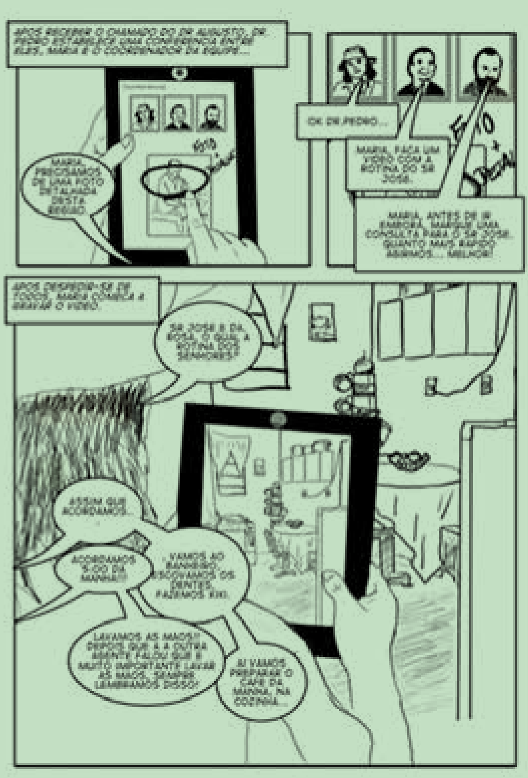
The aim of these storyboards was to illustrate as vividly as possible for Health Agents how the designs were to work. With the storyboard, we could ask them about what they saw as realistic, what was working, and what they think would not work. Storyboards thus helped us to test some of our beliefs at this stage. Also, they helped Health Agents to identify gaps in our knowledge.

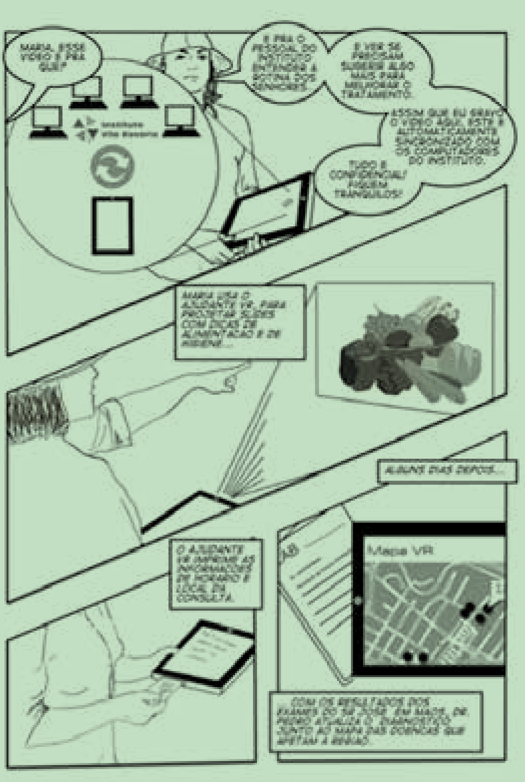

UM DIA DE TRABALHO...
ESTAVA UMA LINDA MANHÃ DE SOL EM VILA ROSÁRIO.
MARIA ACORDOU CEDO, DISPOSTA A SOLUCIONAR O PROBLEMA DO SR. JOSÉ BARBOSA.
APESAR DE TER TODOS OS SINTOMAS DO RETORNO DA TUBERCULOSE, ELE SE NEGA A BUSCAR AJUDA ESPECIALIZADA.
ONDE ESTÁ MEU AJUDANTE VR?
PRECISO ACHAR ONDE MORA O SR. JOSÉ.
O AJUDANTE CARREGA AUTOMATICAMENTE A BATERIA SOLAR.
MARIA PERCEBE QUE A RUA DO SR. JOSÉ NÃO CONSTA DO MAPA OFICIAL!!
ELA FAZ A MARCAÇÃO DA NOVA RUA, SOBRE UMA IMAGEM DE SATÉLITE...
OH DE CASA!!
OI MARIA... ENTRA!!
O MARIA, NÃO QUERIA TE INCOMODAR! MAS A ROSA, FICA PREOCUPADA COM MINHA SAÚDE!
COF... COF COF!! ISSO É SÓ UMA GRIPE!
POSSO GRAVAR NOSSA CONVERSA?
CLARO MARIA! FIQUE A VONTADE!!

30/10/2010
Sr. José Barbosa


SR. JOSÉ, ESTOU VENDO UMAS MANCHAS DIFERENTES EM SUA PELE.
VOU TIRAR UMAS FOTOS E ENVIAR PRO DR. PEDRO.
OK?
CLARO!

PRONTO, EU JÁ DITEI O TEXTO E ESCOLHI AS FOTOS E O ÁUDIO DA CONVERSA, PRA MANDAR PRO DR.
AGORA É SÓ ENVIAR APERTANDO ESTE BOTÃO!
DR. PEDRO TRABALHANDO EM SEU CONSULTÓRIO.
UMA MENSAGEM URGENTE DE MARIA... O QUE SERÁ?
VOU CONFERIR TUDO NO AJUDANTE VR...
O CASO É MAIS GRAVE DO QUE PENSAVA.
VOU CONTACTAR O DR. AUGUSTO.


APÓS RECEBER O CHAMADO DO DR. AUGUSTO, DR. PEDRO ESTABELECE UMA CONFERÊNCIA ENTRE ELES, MARIA E O COORDENADOR DA EQUIPE...
MARIA, PRECISAMOS DE UMA FOTO DETALHADA DESTA REGIÃO.
OK DR. PEDRO...
MARIA, FAÇA UM VÍDEO COM A ROTINA DO SR. JOSÉ.
MARIA, ANTES DE IR EMBORA, MARQUE UMA CONSULTA PARA O SR. JOSÉ. QUANTO MAIS RÁPIDO AGIRMOS... MELHOR!
APÓS DESPEDIR-SE DE TODOS, MARIA COMEÇA A GRAVAR O VÍDEO.
SR. JOSÉ E DA. ROSA, O QUAL A ROTINA DOS SENHORES?
ASSIM QUE ACORDAMOS...
ACORDAMOS 5:00 DA MANHÃ!!
...VAMOS AO BANHEIRO, ESCOVAMOS OS DENTES, FAZEMOS XIXI.
LAVAMOS AS MÃOS!! DEPOIS QUE A A OUTRA AGENTE FALOU QUE É MUITO IMPORTANTE LAVAR AS MÃOS, SEMPRE LEMBRAMOS DISSO!
AÍ VAMOS PREPARAR O CAFÉ DA MANHÃ, NA COZINHA...


MARIA, ESSE VÍDEO É PRA QUE?
É PRA O PESSOAL DO INSTITUTO ENTENDER A ROTINA DOS SENHORES.
E VER SE PRECISAM SUGERIR ALGO MAIS PARA MELHORAR O TRATAMENTO.
ASSIM QUE EU GRAVO O VÍDEO AQUI, ESTE É AUTOMATICAMENTE SINCRONIZADO COM OS COMPUTADORES DO INSTITUTO.
TUDO É CONFIDENCIAL! FIQUEM TRANQUILOS!
MARIA USA O AJUDANTE VR, PARA PROJETAR SLIDES COM DICAS DE ALIMENTAÇÃO E DE HIGIENE...
ALGUNS DIAS DEPOIS...
O AJUDANTE VR IMPRIME AS INFORMAÇÕES DE HORÁRIO E LOCAL DA CONSULTA.
Mapa VR
COM OS RESULTADOS DOS EXAMES DO SR. JOSÉ EM MÃOS, DR. PEDRO ATUALIZA O DIAGNÓSTICO, JUNTO AO MAPA DAS DOENÇAS QUE AFETAM A REGIÃO.

8

Giving the Program an Identity

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Visual Identity

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Health Agent Kit
and Instructions

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Oscar the Mascot

The first task of the design process was to create an identity for the Vila Rosário program. It had to be understandable and recognizable to people in Vila Rosário. It could not be threatening, too cold, or too formal, and it had to avoid associations to institutions the locals did not trust, like the police.

Another reason for building an identity for the program was that as it had become clear that the program needed to be a combination of hi-tech and lo-tech elements, there would be many designs. Keeping them consistent was a challenge that had to be dealt with, somehow. The best way to do this was to develop an identity that could give direction to more detailed design work.

The task was broken into several subtasks. First, there was a need to develop a visual identity for the program. After having settled it, the second subtask was to use the identity in the program. As shown below, this involved several things for Health Agents.

FIGURE 8.1
Final logo designed to be applied in a circular or regular square shape

VISUAL IDENTITY

The first subtask was creating a high-level visual identity for the program. This core identity had to work in the community, and it had to signal people in Vila Rosário who were a part of the Health Agent program. The design I developed with Marcelo is in Figure 8.1.

The concept of the logo is a transformation of a common flower clover, specifically a three-leaf clover that grows and adapts to practically any soil type and can survive many adversities. Sometimes it becomes a four-leaf clover, which is regarded as a symbol of good luck. As a logo, it suggests that the community is fortunate and Health Agents and their project at IVR strive for building a better community and that they believe in the potential of community.

There are other aspects in the logo as well. It represents the stem of the plant that takes its nutrients from the soil itself. It tells about a community that wants to be self-sustainable, to make use of its own resources and strength. The logo is also developed into mosaics, which was one of craft classes offered by the IVR. The flower is also styled as a mill: it gives clean, local energy to a mill in Vila Rosário. The mill represents a sustainable society that respects the basic principles of responsible development.

It uses energy harvested from nature in an ecological way in the pursuit of local power. It reintegrates Vila Rosário into the mainstream society. The mill is also about a community that pools its resources for a common cause. Finally, flowers are dynamic and grow: the logo represents constant search for a better future.

HEALTH AGENT KIT AND INSTRUCTIONS

The second subtask consisted of creating designs that would make the status of Health Agents somehow visible. As we have seen earlier in this book, Health Agents were recruited locally. Even when on duty, they dressed in their normal clothes and used their normal bags. Even though this works in the case of those agents who were from the community and who were known there, this was a handicap in terms of spreading the program. Health Agents, I thought, should be recognizable even for those who did not know them in person.

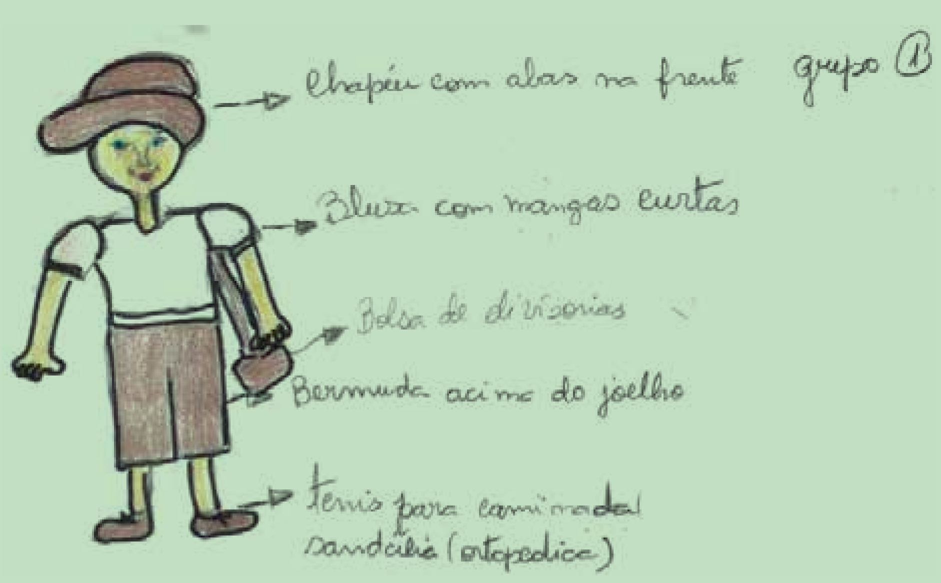


FIGURE 8.2
A sketch of the uniform, done with Health Agents

FIGURE 8.3
A sample of elements of the Vila Rosário uniform

For this reason, we designed a uniform for Health Agents. We started the process of developing the uniform by sketching it with Health Agents (Figure 8.2). The uniform had a hint of medical world conventions, but was local in terms of its colors and materials. The uniform consisted of a work coat, t-shirt and a hat, which was needed in tropical sun. It also consisted of a folder and a bag (Figure 8.3).

Finally, Marcelo and I created instructions for using these designs. We knew that the program would run for years after our study, and we could not be there explaining the identity all the time. For this reason, we created cartoons that described how the uniform was to be applied. Below is one cartoon.

Chapter 9 below shows how the identity was used to create coherence to other designs we created.

Identifying illness

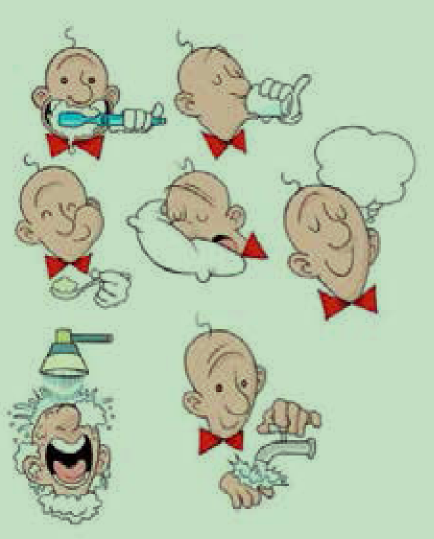
Guiding the patient to treatment

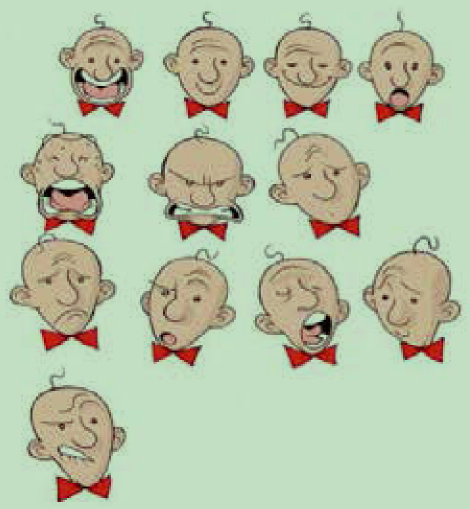
Advising the patient's family

Following up the treatment

FIGURE 8.4
Cartoon explaining how
the identity works

FIGURE 8.5
Oscar the Mascot





OSCAR THE MASCOT

The final thing we developed to give the program a friendly face was a mascot, who appeared in most designs. Unlike other characters, the mascot was not based on local characters. Rather, he was a comic character, a clown who did most things wrong, but somehow always managed to get by. For us, this character gave an opportunity to show how things like taking care of hygiene can be done properly, and what follows when they are done wrong.

The name of the character was Oscar. He was a dandy, always dressed in a bow-tie. He was impulsive and not able to resist his desires, that were typically prompted by something he had seen or something he had heard. His facial expressions were exaggerated, as were his gestures. He was sometimes greedy, angry and self-centered, but good-natured, well-meaning, and usually in a good mood. Oscar's face had clown-like features. We wanted to keep him distant from real people by turning him into a stereotype rather than building him around local characters.

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Having settled the preliminaries in terms of content and the design program, I started to do detailed designs for Health Agents in Vila Rosário with Marcelo. These designs were meant to provide tools for Health Agents to do their work better in the community. They targeted several aspects of their work. First, some designs were instructional, aimed at giving Health Agents means to educate Vila Rosário's inhabitants about disease, hygiene, and nutrition. Second, some designs aimed at assisting them to gather data for the purposes of research and monitoring community health, especially among its most hidden pockets. Third, there were designs that were aimed at making Instituto

Vila Rosário a livelier place, a community hub from which people could learn things to take away back home. Finally, some designs were targeted at improving communication between Health Agents and medical experts.

As I explained earlier, the suite of designs we developed were mostly lo-tech, despite our initial hi-tech aim. The reasons were simple. We did not see much point in introducing information technology into an environment in which electricity is unreliable, tropical heat and humidity ruins it quickly, and in which it would quite likely be stolen in a few days. Its role became smaller than in the initial aims: it became a window from Vila Rosário to the medical establishment.

Before going into the actual designs, I would like to repeat: my book focuses on the research process. The final designs and their development are described in more detail in Marcelo Judice's doctoral thesis (M. Judice 2014). In this chapter, I will give examples of designs rather go through each one of them in detail.

LO-TECH DESIGNS FOR PEOPLE IN VILA ROSÁRIO

Most designs were lo-tech. Because of the limitations of the Web, we could not rely on it. The aim of our lo-tech designs was to raise awareness about the main threats to public health: poor hygiene, poor nutrition, and contagious diseases. We wanted to create designs that Health Agents could use to ease their daily work. In terms of design, we wanted to introduce local character to our designs and avoid preaching knowledge. Instead, we wanted the designs to be fun and artistically interesting. This has been one of the working hypotheses of empathic design, where our research started (see Koskinen et al. 2003; Mattelmäki 2006).

Educational posters

The bulk of the designs were posters that had an educational purpose. In terms of their content, the posters focused on themes we had identified earlier in our fieldwork. In terms of their design, we followed the principles explained in Chapter 7. They translated our design themes into a language familiar to people in Vila Rosário and at the Institute. Through this common "language game" that we had identified and developed during our fieldwork, we tried to reach a better relationship with members of community, specialists, volunteers, and other people involved in the Instituto Vila Rosário project. They used characters created earlier to communicate health-related information. The posters had been planned to reach health issues primarily from an individual standpoint, but they have elements targeted at the community as a whole.

The plan was to give posters to Health Agents, who could use them to teach better habits to patients and their families. Thus, they described typical situations in which people could get sick; how they could make better choices regarding food; and how they could take better care of hygiene. They were meant to support a process Health Agents went through in their work (see the closing section of Chapter 4); the aim was to make people think about their habits, and learn better ways. They also invited community members to go to the Instituto Vila Rosário to make them aware of what kind of services it offers.

The posters were planned to reach different groups of people. All information was communicated to Health Agents with colors. Yellow meant disease, blue hygiene, green nutrition, while grey/silver meant new communication technologies.

Thus, the posters were designed to motivate and to stimulate the community to reach certain objectives. The cultural traces, values and behaviors are important variables to

be considered when the designer is developing the products. As the Health Agents repeatedly told us, as a designer you should develop posters, booklets or other kinds of information systems with characters and messages that are connected with the reality of that community and suitable to their needs. If not, the designs are not going to motivate people who will use the product.

Our first idea was to develop posters together with the Health Agents. Therefore, during the fieldwork, we started a brainstorm session to catch their ideas. After getting a sense of the most important issues to be approached, we started to think about the posters designs. Health Agents' first suggestion was to use large photographs. For them, photographs are excellent media to motivate the community. When we wondered if photographs are the only media they can think about, they told us that they think photos are very efficient because they show the reality, and with them, you can juxtapose many different realities. They had cameras and they could develop the ideas by themselves based on their photos. We inquired them if they often applied these techniques. They told that it is expensive to print photos and it is not easy to find comparable contexts that would help them to organize their ideas efficiently. Sometimes they need an older person; sometimes they do not find a house that shows the reality they need to approach. So, in reality, they had an idea, but they never realized it. We told them that this is a wonderful beginning for us; we could develop some storyboards with them, using the photos they had taken for us. As designers, we also started to discuss with the Health Agents about the implications of spreading enlarged photographs across Vila Rosário.

Based on what they told us, we saw that the cost of developing posters using photos was higher than our budget. Next we asked Health Agents to tell about what kinds of

FIGURE 9.1
Studies of colors of different labels according to subject.

FIGURE 9.2
Digital inclusion poster: Everyone can learn how to use a computer.

FIGURE 9.3
Poster of digital inclusion: come to learn with us.

FIGURE 9.4
Poster of digital inclusion: come to learn how to use a computer.

FIGURE 9.5
Poster of Tuberculosis Awareness: Tuberculosis has a cure!

FIGURE 9.6
Nutrition poster: learn how to feed.

FIGURE 9.7
Nutrition poster: feed well, live well!

FIGURE 9.8
Nutrition Poster: Do you know how to feed well? Come learn with us!

FIGURE 9.9
Hygiene poster: Got dirty? You should clean yourself!

FIGURE 9.10
Hygiene poster: Do you know how to wash your hands? Are you sure? Come learn with us!

FIGURE 9.11
Hygiene poster: Keep yourself clean!

FIGURE 9.12
Hygiene poster: Don’t let the germs have a party on your body!

DESIGNING FOR VILA ROSÁRIO

elements we should add to photos to develop them into posters that would send the right message to people in Vila Rosário and motivate them to change their ways. They had some objections to this idea. In their opinion, we would need to have people from the community to pose for us. They thought families would be unwilling to let us take these photos and use them in our research, for two reasons. First, if a family is photographed and these photos are reproduced in great dimensions and spread across the community to illustrate health problems, this would stigmatize these families. Second, they emphasized that these photos would give an impression of false charity. The families could use the photos as an opportunity to act as people in poverty who need to receive assistance with no strings attached.

We also thought that we would have problems in constructing scenarios relative to the present, past and future of the families. We would have to count too much on our imagination. A more sophisticated production was not suitable for us because of budget constraints, and we would have difficulties in finding enough people to represent people from different age and social groups.

After ruling out the idea, Health Agents suggested that we should have a better understand of health in Vila Rosário to help to improve it. Custodia suggested building a photo album through storytelling because in her mind this would be easy to reproduce, and for that specific situation, the photos could work well; photos would be realistic (see her story about Maria in Chapter 5). Based on her experience, she said that if the aim was to catch the attention of the population at large, posters and cartoons work well, but they should portray life in terms of Vila Rosário and how Health Agents want to transform it. The thing to avoid is strengthening the population's perception of their

reality; they wanted to modify it rather than reinforce existing behaviors. Posters should start the change.

At this point, we started to rethink the function of posters. Our new approach was to think about posters as a way of spreading information about the health care path from diagnosis to cure. The Health Agents came up with the possibility of spreading the posters around Vila Rosário and leaving some of these in families rather than making an advertising campaign-style intervention. They wanted to show right behaviors to specific patients, families, and their friends. They suggested a guerrilla tactic: leaving the posters with people who can spread the message. Health Agents need help in placing posters in key community points, such as schools, hospitals, and churches.

The posters had to be small leaflets rather than big photographs. They had to have as little text as possible. They could not build on real people to avoid stigmatization. For these reasons, we ended up doing small posters with minimal text fields, using unambiguous graphic designs to underline the main message of the poster, and using cartoon-like characters we had developed in our study. These were simple to reproduce; the only thing that was needed was a local print shop, and even a regular printer was enough (Figures 9.1–9.12. There are some posters that were done before the redesign of the symbol).

These posters have an important role showing the community that Vila Rosário Institute is doing important work in empowering their community. They also detailed the areas approached by the program, and they invited people to visit the Institute. Years later, the Health Agents see the posters as one of the key designs that help them to inform people. Their main consequence is that the population has learnt about the Institute and its objectives much more efficiently than through the grapevine.

Scripting Behaviors: Booklets

Custodia made another important remark in the poster critique session. She thought booklets would work better than advertising-style photographs. They have a lot of more content. She showed us one booklet she uses in her work that brings good results. People are willing to read it and they find it easy to visualize content issues with it. People can interact with the drawings and they understand the images. In consequence, they can understand the message transmitted.

The booklet she showed us reproduced a reality very similar to Vila Rosário's. It approaches and motivates different publics, from children to the older ones. It used an amusing language. It was colorful. It was funny and very captivating. People who Custodia took care of understand the message well, even though the message could very graphic about issues like the consequences of untreated tuberculosis. Receiving this information from a cartoon meant that people were not too shocked, even about the most severe consequences of the side effects of the treatment.

Another important thing Custodia told us was that we have to think about the patients' reaction to the material because the material can produce the opposite effect to the intended one. For example, people can get afraid of the treatment or concerned about being stigmatized. The main reason she had found the tuberculosis cartoon useful was its didactics. As patients and their families pay attention to the explanation, she can use it as a storybook and can build scenarios. They cannot afford cartoons, so the kids like to have the booklets to read and play with. The most important thing, in her opinion, is that she can show the different stages of the tuberculosis treatment, and make people aware of how the treatment works.

Following spread:

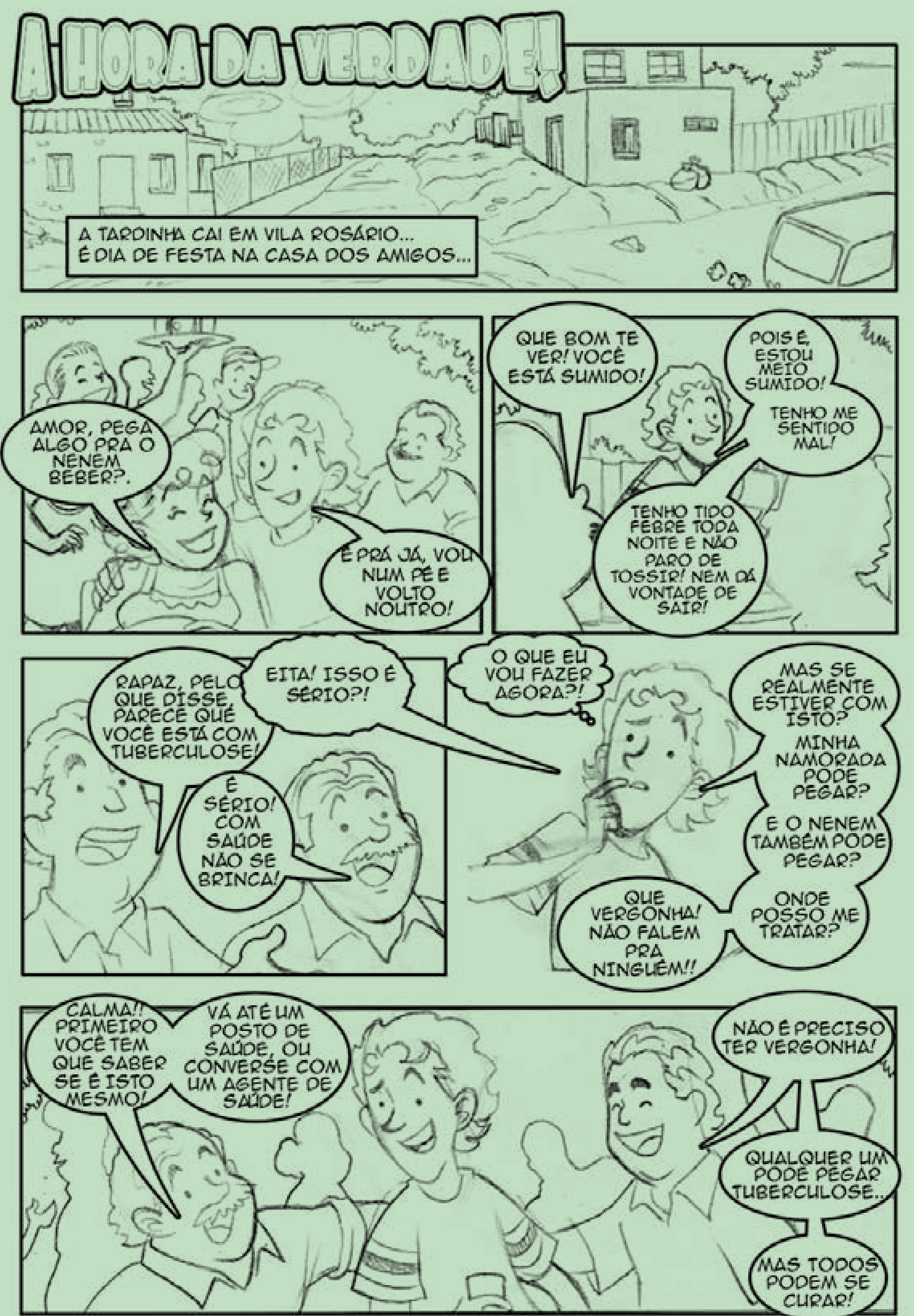
FIGURE 9.13
Final version of TB booklet: explaining every symptom they should be aware of.

FIGURE 9.14
Final version of TB booklet: final page - informations about Instituto Vila Rosário - if someone decides to look for help they will know where they should go.

Another issue was comprehension. Health Agents showed us three examples of booklets using cartoons that had no effect with people in Vila Rosário. They were not motivated to interact with these. We asked why, and they told us that one of the booklets was too difficult, and another had only wrong kinds of people: all blond and red haired in nice clothes. If people from the community do not identify themselves with the cartoon, they will reject the product. Custodia stressed that we need to pay attention to the local context and to express the values and behaviors of local people in the booklet. Other Health Agents agreed. In essence, we had to try to capture the spirit of Vila Rosário's inhabitants and build it into our cartoons.

For these reasons, we decided to use comics as a form of communication. Comics were popular in Vila Rosário. This format allowed us to describe in detail how things like the symptoms of disease are manifested in life, and what kinds of actions ought to be taken when they arise. The format also made it possible to show why diseases can be dangerous not just to the carrier, but also to others around. These comics were drawn in *manga* style using characters we had developed earlier form local people. These stories also had many local details; the story world was made to be local and familiar to readers. They had a friendly tone, stressing that although the treatments may have side effects, they can be overcome, and the disease is worse than the cure.

Figures 9.13–9.14 give an example of a comic, which tells about the importance of paying attention to symptoms of a disease. In this comic, a young, sweaty man arrives at a party


A HORA DA VERDADE!
A TARDINHA CAI EM VILA ROSÁRIO... É DIA DE FESTA NA CASA DOS AMIGOS...
AMOR, PEGA ALGO PRA O NENEM BEBER?.
É PRÁ JÁ, VOU NUM PÉ E VOLTO NOUTRO!
QUE BOM TE VER! VOCÊ ESTÁ SUMIDO!
POIS É, ESTOU MEIO SUMIDO!
TENHO ME SENTIDO MAL!
TENHO TIDO FEBRE TODA NOITE E NÃO PARO DE TOSSIR! NEM DÁ VONTADE DE SAIR!
RAPAZ, PELO QUE DISSE, PARECE QUE VOCÊ ESTÁ COM TUBERCULOSE!
EITA! ISSO É SÉRIO?!
É SÉRIO! COM SAÚDE NÃO SE BRINCA!
O QUE EU VOU FAZER AGORA?!
MAS SE REALMENTE ESTIVER COM ISTO?
MINHA NAMORADA PODE PEGAR?
E O NENEM TAMBÉM PODE PEGAR?
ONDE POSSO ME TRATAR?
QUE VERGONHA! NÃO FALEM PRA NINGUÉM!!
CALMA!! PRIMEIRO VOCÊ TEM QUE SABER SE É ISTO MESMO!
VÁ ATÉ UM POSTO DE SAÚDE, OU CONVERSE COM UM AGENTE DE SAÚDE!
NÃO É PRECISO TER VERGONHA!
QUALQUER UM PODE PEGAR TUBERCULOSE...
MAS TODOS PODEM SE CURAR!

A HORA DA VERDADE!
A TARDINHA CAI EM VILA ROSÁRIO...
É DIA DE FESTA NA CASA DOS AMIGOS...
AMOR, PEGA ALGO PRA O NENEM BEBER?.
É PRÁ JÁ, VOU NUM PÉ E VOLTO NOUTRO!
QUE BOM TE VER! VOCÊ ESTÁ SUMIDO!
POIS É, ESTOU MEIO SUMIDO!
TENHO ME SENTIDO MAL!
TENHO TIDO FEBRE TODA NOITE E NÃO PARO DE TOSSIR! NEM DÁ VONTADE DE SAIR!
RAPAZ, PELO QUE DISSE, PARECE QUE ESTÁ COM TUBERCULOSE!
EITA! ISSO É SÉRIO?!
É SÉRIO! COM SAÚDE NÃO SE BRINCA!
O QUE EU FAÇO AGORA?!
MAS SE REALMENTE ESTIVER COM ISTO?
MINHA NAMORADA PODE PEGAR?
E O NENEM TAMBÉ PODE PEGAR?
ONDE POSSO ME TRATAR?
QUE VERGONHA! NÃO FALEM PRA NINGUÉM!!
CALMA!! PRIMEIRO VOCÊ TEM QUE SABER SE É ISTO MESMO!
VÁ ATÉ UM POSTO DE SAÚDE, OU CONVERSE COM UM AGENTE DE SAÚDE!
NÃO É PRECISO TER VERGONHA!
QUALQUER UM PODE PEGAR TUBERCULOSE...
ESTA DOENÇA TEM CURA!!

NA MANHÃ SEGUINTE...
AMOR, PROCURA A AGENTE DE SAÚDE!
VOU PERGUNTAR PRA VIZINHA, ELA DEVE SABER O QUE FAZER
OI! ONDE EU ACHO A AGENTE DE SAÚDE?
OLHA ELA CHEGANDO ALI!
OI PESSOAL!
O MENINO NÃO PÁRA DE TOSSIR!
VAMOS VER SE VOCÊ TEM QUE IR AO POSTO DE SAÚDE...
A TOSSE COMEÇOU HÁ 3 SEMANAS?
TEM FEBRE NO FINAL DA TARDE?
TEM MUITO SUOR DURANTE A NOITE?
ESTÁ EMAGRE-CENDO SEM MOTIVO?

6 MESES DEPOIS...
OLHA SÓ A FAMÍLIA!
ESTÁ CURADO?
ESTAMOS CHEIOS DE SAÚDE!!!
ALÉM DE SAUDÁVEIS, OLHA COMO ESTAMOS FELIZES E BONITOS!

TUBERCULOSE TEM CURA!
CONHECE ALGUÉM COM ALGUM DOS SINTOMAS QUE APARECERAM NA HISTÓRIA?
DIGA PARA PROCURAR UMA AGENTE COMUNITÁRIA OU UM POSTO DE SAÚDE!
MAIORES INFORMAÇÕES:
INSTITUTO VILA ROSÁRIO
R. GENERAL TAUMATURGO, LOTE 18, QUADRA 4, DUQUE DE CAXIAS, RJ.
TELEFONE: (021) 3135 5406
LIGUE SEM PAGAR: 0800 61 1997

Previous spread:

FIGURE 9.15
The final version of the tuberculosis booklet: this page explains every symptom people should be aware of.

FIGURE 9.16
The final version of tuberculosis booklet: the final page gives information about Instituto Vila Rosário. In case someone decides to look for help they will know where they should go.

to see his girlfriend. After a while, two older men tell him to pay attention to his sweatiness, and consult a doctor because this is one of the symptoms of tuberculosis. When the young man gets scared, he is assured by the older men that tuberculosis is treatable, but only if he gets a proper diagnosis and takes his medication. They tell him to contact a Health Agent to discuss his symptoms. The young man is relieved.

Figure 9.13 is also an example of how we developed the booklet together with Health Agents. This page was sent to Health Agents as a beginning of the booklet. We asked them to color it and tell us the rest of the story. Thus, we sent this page, color pencils, pens and paper to the health agents, who then finished the story. Figure 9.14 shows how they colored it. Of course, this is the final, computer-colored version, but colors are based on their work. On the final page of the booklet, there is an information page about IVR. That page provided readers important information about IVR from the health agents' point of view. They think that the booklet can help people to look for help.

These comics helped to instruct people of proper behaviors in the face of possible diseases. Like in the case of the posters, the main aim was to create awareness in the community and sensitize its population to diseases when they are still treatable. This format, just like the posters, was employed because Health Agents had warned us of using communication formats too serious. It was better to sugar-coat the message.

Another booklet focused on nutrition. The language applied to the nutritional booklet was based on the words, sounds,

gestures used by people from the community, specialists, and other people related to Vila Rosário's project. We cut pieces of photos Health Agents had taken for us. We also used textures from Vila Rosário to develop some patterns, and we drew over the photos and used a drawing similar to the ones people involved in the project had drawn for us. One of our objectives in doing so was to show to the Health Agents that even the simplest drawings could present an efficient result.

We also developed other booklets. For example, one of the booklets was about nutrition. Importantly, these booklets were also used as starting points for other designs, like games. Our attempt was to create booklets that could be taken home. They were also supposed to be colorful and interesting enough to function as comic strips that children would be interested in. By integrating games with the booklets, we tried to find a way for children to internalize the contents even better.

Education to Vila Rosário: Stories and Games in Nutritional Workshops

While posters and cartoons and similar designs were meant to support Health Agents' work outside the Instituto Vila Rosário, we also wanted to lower the barrier of coming into the Instituto. This would make the Instituto a better part of community life, and it would also help to avoid stigmatization.

To bring people into the Instituto, we wanted to program the space with a series of workshops we developed for Instituto Vila Rosário. These workshops were community events that brought people to the institute to learn about disease, hygiene, and nutrition. For the workshops, we developed formats games and stories that would be educational and easy enough to learn as to be taken home, so that parents could play them with

children and that way teach them. We wanted to avoid giving the impression of *ex cathedra* lecturing.

The main question we addressed in these workshops was how to create nutritional awareness among Vila Rosário´s community members through nutrition, education and information. For us, the workshops were a didactic approach aimed at raising consciousness about the importance of nutrition and at sharing knowledge, attitudes and practices about proper nutrition especially among young girls, who are going to be mothers one day.

The questions we addressed were difficult: what are the main nutritional problems in Vila Rosário? How are they affecting the community? Who is most affected? What are the impacts on the social, economic and cultural life? To develop designs, we needed to identify day-by-day experiences of the community in relation of food. We also paid attention to food borne diseases like cholera, which is often waterborne, but also many foods that transmit infection, including ice and raw or unprocessed seafood.

Another question we worked through in the workshops was demographic. What are the groups affected most by alimentary problems, and how are they affected?

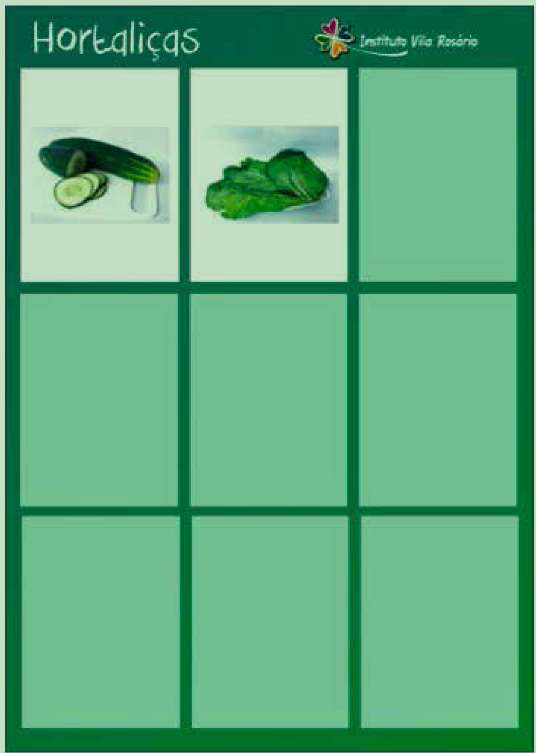
In this part of the design program, we followed the doctors' advice and targeted infants and children under five by creating designs for pregnant and lactating women, who are among the most vulnerable people in the community. Most factors causing problems to these women in Vila Rosário were beyond our powers, like the absence of income and education. However, malnutrition contributes directly to increased poverty and, in the long term, has a negative effect on a country's economic growth.

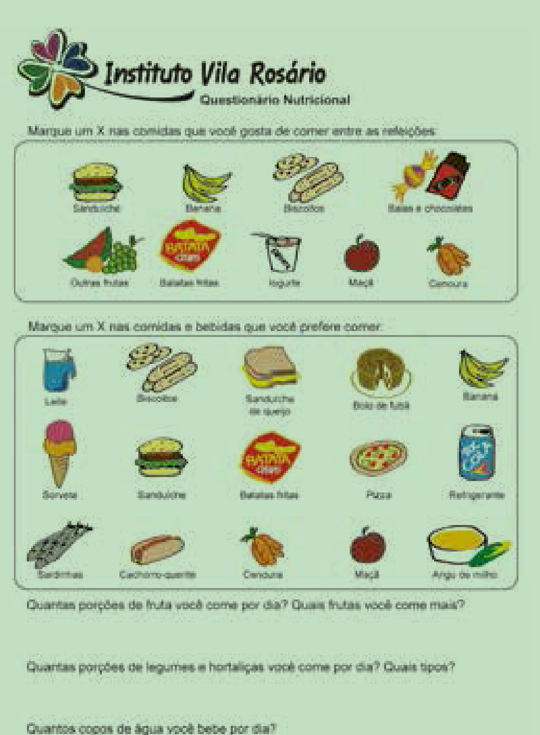
> "Well-nourished women run fewer risks during pregnancy and childbirth. Well-nourished children perform better at school, become healthier adults, and can offer a better start in life to their

FIGURE 9.17
Nutritional booklet, inspired in the community's pictures. This page was based on picture drawn by a Health Agent. See Chapter 8).

FIGURE 9.18
Nutritional booklet. Presenting fruits and vegetables and its benefits.

FIGURE 9.19
Board game with some cards to teach how to recognize greens




Instituto Vila Rosário

Questionário Nutricional

Marque um X nas comidas que você gosta de comer entre as refeições:

Sanduíche — Banana — Biscoitos — Balas e chocolates

Outras frutas — Batatas fritas — Iogurte — Maçã — Cenoura

Marque um X nas comidas e bebidas que você prefere comer:

Leite — Biscoitos — Sanduíche de queijo — Bolo de fubá — Banana

Sorvete — Sanduíche — Batatas fritas — Pizza — Refrigerante

Sardinhas — Cachorro-quente — Cenoura — Maçã — Angu de milho

Quantas porções de fruta você come por dia? Quais frutas você come mais?

Quantas porções de legumes e hortaliças você come por dia? Quais tipos?

Quantos copos de água você bebe por dia?

FIGURE 9.20
Example of a Health Agent Questionnaire (it was designed before the symbol redesign).

FIGURES 9.21 - 9.22.
Maps and a visualization tool of data

own children... [How we can modify the actual situation] Nutrition policies: these policies should combine short-term strategies such as nutrition advocacy with comprehensive, long-term strategies that include changing household and individual behaviors and improving levels of female education and status in society."
(Holistic approach – with short, medium and long terms actions)[22]

As I said above, we integrated booklets and games. The idea was to use redundancy to make sure the contents would be read and internalized. In Figures 9.17–9.18, there are examples of booklets about nutrition. Figure 9.19 gives an example of a game we designed to bring nutrition home. It is a simple board game children could play, to learn to recognize nutritious plants with their parents. Games also taught children how to maintain hygiene and how to avoid some other behaviors that expose them to diseases, like dirty water.

DESIGNS FOR DOCTORS AND HEALTH AGENTS: THE NUTRITIONAL QUESTIONNAIRE

Some designs were targeted not at people in Vila Rosário, but at the health care community involved in the project. They were meant to improve medical information about the community. Health Agents were the best-placed people to know intimately what was going on among the poorest elements of Vila Rosário. Many of these truly poor people were also disease carriers, and hence of particular interest to public health programs. If their situation could be improved, there would be much less contagion in the community. The problem was how to connect to these people, and how to elicit reliable information easily from these poor people, who were often illiterate as well.

22 http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/LACEXT/0,,contentMDK:21161481~menuPK:2246555~pagePK:2865106~piPK:2865128~theSitePK:258554,00.html. Accessed **

In answering to this call, we decided to try a visual approach. We developed a series of visual questionnaires that were easy to fill in house visits, and that were easy to code into a data base in Instituto Vila Rosário. As we have seen in Chapter 6, one of the aims of Health Agents was to collect data about health and also about nutritional problems in Vila Rosário. To make this task easier, we asked what kinds of problems are there, how much people know about them, how this knowledge manifests in life, how the population is affected by nutrition, and how the social, economic and cultural life of the community is affected by nutrition. Figure 9.20 gives an example of the visual tool we developed for data collection.

These data were placed on a map, and we also suggested building a visualization tool for zooming in and out from these maps. This tool was not built due to the lack of resources, however, and remained but a sketch (Figures 9.21–9.22).

THE IVR WEBSITE AS A WORMHOLE TO MEDICAL EXPERTISE

As it is clear by now, although the initial aim of the research project was to build information infrastructure for Vila Rosário, our fieldwork led quickly into a redefinition of the task. Instead of building designs on a high-tech platform, the bulk of the work went into developing cheap, easily replaceable designs that had little value outside the situations of their use. The Web, however, remained a part of our design program, and it got quite a prominent place in it, even though its role became very specific. It became a communication link from Vila Rosário to the medical establishment outside the community, and back. The reasons for this reframing came from several sources in our data, including interviews, observation, and empathy probes that showed a high-

tech only solution would not be viable. Table 9.1 collects all studies we did in developing the website.

The main purpose of the website was to connect Health Agents and doctors in Rio de Janeiro's universities and research institutes. For Health Agents, it was important to get support in situations of doubt in diagnosis, for example. For doctors, it was important to have a tool that helped them to get an overview of Health Agents' work in Vila Rosário. These two became the main purposes of the web page.

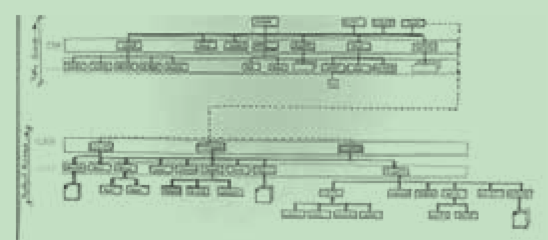


FIGURE 9.23
A sketch of the structure for the health portal

In developing the Vila Rosário website, we first benchmarked several websites and decided to go for a fairly traditional hierarchical architecture that had two separate areas, one publicly accessible, another having a restricted entry. After defining the basic architecture, we created a structure for the system. The structure was a collage of two sources, the themes we had identified, and the organization of the Instituto. We reasoned that the website had to give people a Who's Who view of Instituto Vila Rosário and also their contact information. It furthermore needed a topical section about health issued in the community. This was a curated page of frequently asked questions, and it was also to give people an opportunity to discuss their concerns. The site should also describe healthcare projects in the community, have a news section to keep it interesting, and a search function for surfers. All this was to be public.

Behind the public facade was a login that provided access to a restricted area that built on a database. The restricted area was targeted primarily at Health Agents, and it was to function

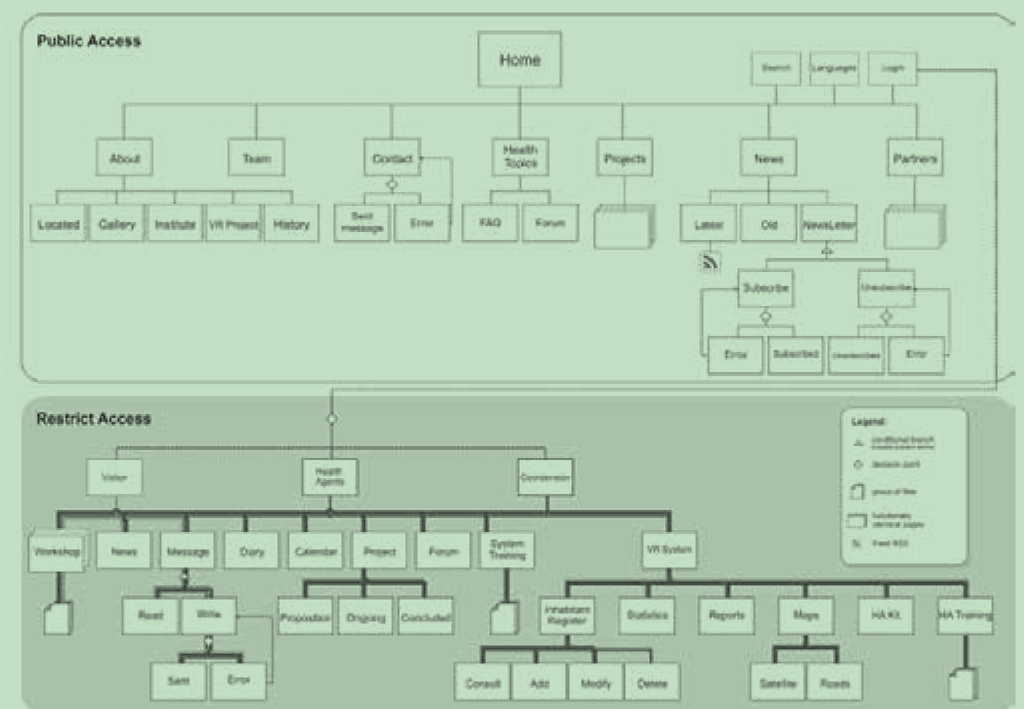
as a working space for Health Agents. It had information about workshops and other events. It also had a calendar, project information, information about training, and a research section that had statistics, maps, and information about the Health Agents' kit that we had developed for Instituto Vila Rosário.

The research section had a place in which Health Agents could log in data they had gathered in their work. This section was to provide doctors outside the community information about what was happening in it. A messaging function, on the other hand, gave Health Agents access to doctors. The final structure of the site is described in Figure 9.24.

TABLE 9.1 WEB DEVELOPMENT: THE PROCESS	Research	Strategy and requirements to Information Architecture
	Skype interviews from Helsinki, validated though probes and ethnography. Benchmarking of websites (see M. Judice 2014) and Dr. Costa Neto's database. Mindmaps, brainstorms, personas and scenarios in Helsinki. Usability tests and thinking aloud protocol analyses of some benchmarked websites. Workshops in Helsinki. Feedback from Namibia used as feedback in Vila Rosário. Key sources: (Carroll 1999), (Jordan and Henderson, 1995), (Bastien & Scapin 1993), (Dias, 2001). (Heemann, 1997), (Dumas & Redish, 1999), (Hackos & Redish, 1998), (Osborn, 1975), (Cooper, 1995).	Decisions on technical requirements, functional specifications, and content. Information architecture. Content mapped to the pages. Key source: Jesse James Garrett (2010)

The second design task was to create a skin and user interface for the portal. The skeleton of the portal came from the structure created earlier, which also gave a structure to the interface. Hence, the main page contains level 1 elements of the public access area of the page (Figure 9.25). Health Agents, for instance, got access to the restricted part which had more project information and data. As Figure 9.26 shows, our icon design was casual and interpreted standard icon items in local terms to reflect local sources, colors, and interests as we had seen during the field work. As Figures 9.27 and 9.28 show, as soon as the structure of the site was established, navigation was straightforward, and based directly on the structure.

Strategy and requirements to Visual Design	Implementation strategy and requirements to the internet	Other important points considered
Creating wireframes and validating them with Cr. Castello Branco. Creating layouts in Photoshop. Paper prototyping with Health Agents, Dreamweaver mock-ups.	Buying a domain name, choosing a host, developing final templates, designing interactions between pages, decisions about Web technologies (html, Flash, conent management system, blog features, Joomla).	How to promote the website, how to keep it fresh, who will be responsible for updating, frequency of updates, who can change the site


Public Access
Home
Search
Languages
Login
About
Team
Contact
Health Topics
Projects
News
Partners
Located
Gallery
Institute
VR Project
History
Sent message
Error
FAQ
Forum
Latest
Old
NewsLetter
Subscribe
Unsubscribe
Error
Subscribed
Restrict Access
Visitor
Health Agents
Coordenator
Workshop
News
Message
Diary
Calendar
Project
Forum
System Training
VR System
Read
Write
Sent
Error
Proposition
Ongoing
Concluded
Inhabitant Register
Statistics
Reports
Maps
HA Kit
HA Training
Consult
Add
Modify
Delete
Satellite
Roads

Instituto Vila Rosário

Home
About
Team
Contact
Health Topics
Projects
News
Partners
Local area
Multimedia Gallery
Vila's History
Vila Rosário's Project
Languages
Visitor
Health Agent
Coordenator
Search

O Instituto

Quem somos

FIGURE 9.24
The final proposed structure for the portal

FIGURE 9.25–9.26
The main page of the portal and icons (The first version of the website was done before the redesign of the symbol.).

FIGURES 9.27–9.28
An example of navigation

The webpage development was based on empathic design, which has no repeatable process (Koskinen et al. 2003; Mattelmäki et al. 2014). The main spirit of the empathic design is to create or to innovate a method based on what we learnt in context. There is an overall direction, but no step-by-step process, nor a matrix of the process by method. This kind of flexibility and innovative tools make possible to develop a portal trustable and useful for the community's persons.

It is possible to see the implications of our designs on Vila Rosário's daily activities. Some community health agents are using new media and having a digital inclusion. They are able to interact with people from the community through social media and other tools that we never thought to use five years ago. Using the communication style based on Ehn's interpretation of Wittgenstein brought the context language to the "virtual world" (Ehn 1988a).

DESIGNS FOR STAKEHOLDERS: JOURNAL OF VILA ROSÁRIO INSTITUTE

When we were discussing with Health Agents about the best ways to reach the community, we realized that Instituto Vila Rosário is not known well enough in the community. We came up with the idea of somehow publicizing Instituto Vila Rosário's activities. At the same time, we wanted to find a way to narrate useful information about health and nutrition for the whole community.

FIGURE 9.29
Inviting people to take part in the IVR and also explaining facts and myths about tuberculosis

FIGURE 9.30
Introducing some IVR Community Health Agents and also Carla who works at IVR. Showing the TB's symptoms using cartoon language

FIGURE 9.31
Posters in A4 format to be placed where the members of the community think it is important to have this information. This one is about tuberculosis.

FIGURE 9.32
Another poster in A4 format about the courses the IVR offers.

From these two problems, we developed the idea of reaching the community by designing a journal for the Instituto. The journal should use cartoons and posters, and it should be distributed in places where people pass by and in which they should think about issue like tuberculosis, hygiene, nutrition, and the Instituto. The visual language of the journal, naturally, came from design approach.

The stakeholders of the Institute are always searching for and finding some new partners to help improve the quality of life in Vila Rosário. Graphic products are useful in maintaining these contacts, and there is often funding available for these kinds of products as well. For example, with the assistance of Management Sciences for Health,[23] it was possible to design and to print a version of the Instituto Vila Rosário journal. The new visual identity and a colorful publication helped to make the Institute better known. The journal was used as a media channel to promote the Institute, but also to spread information about tuberculosis, to promote the Health Agents, and to spread the word about what the community members should do in case of having the symptoms of tuberculosis. Several stakeholders involved in the IVR project wrote the journal, including some Health Agents. Marcelo and I developed the design, building on the visual identity we had developed for the Institute. Our colleague Nestabolo drew the cartoons building on guidelines from Health Agents.

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MSH/Brasil is a global health nonprofit organization, and uses proven approaches developed over 40 years to help leaders, health managers, and communities in developing nations build stronger health systems for greater health impact.

10

Fieldwork with Designs in Vila Rosário

205
Administering
the first phase

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Participants

210
Tests

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The Helsinki workshops
with a medical expert

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Tests of Redesigns
in Vila Rosário

One of the main recommendations of empathic design is that designs have to be tested with the people they are designed for. In particular, when visual designs play a key role in design, designers cannot just rely on their initial data collection in creating designs. Designs are notoriously ambiguous, and can be interpreted in many ways. This is the case even more when designs are created for people who are very different from the designers. In the case of Vila Rosário, an added problem was that many people in the community were illiterate. Here, the policy produces a procedural step: when designing for a specific group, it is not enough to understand their world before designing things for them; we also have to study whether

our interpretations are correct (see Fulton Suri 2003: 51-52; Mattelmäki 2006:86-98).

For this reason, we were not content with just using probes and our fieldwork as justifications for our designs. We also wanted to have a better ground for saying that our designs make sense in Vila Rosário. The only way to do this was to go back and talk to Health Agents and other stakeholders in the process such as doctors, who were going to be using the system for being updated on Vila Rosário. Doing this avoids the circle in which research leads to designs that are justified by the same research.

Our initial plan was to do the tests in two phases: the first phase was to be done in Brazil having participants from various groups taking part in the Vila Rosário project; the second phase was to be done in Helsinki, where we were working at the time, with an expert stakeholder of the project. However, as some stakeholders suggested changes to our designs in the first phase, we decided to add one more stage to our tests.

ADMINISTERING THE FIRST PHASE

To test the products, we developed two brochures with all the products and formulated some tasks and questions. Then we asked the participants to do the tasks and respond to the questions. In the text in these brochures, we explained how people could do the tests and how important their participation was for improving our work. We also stressed that we were testing the products – that is, our work, not them or their work. We asked them to keep in mind Vila Rosário's context when doing the tests.

We organized the tests to be printed and organized in Brazil. Then the tests were sent to Carla, a volunteer who took care of applying the tests before sending them back to us in Helsinki, where we were based at that time.

We instructed the volunteer by Skype and e-mail about how to apply the tests. We spent one month trying to figure out with her what was the best procedure with the tests: when to apply, which persons are key persons to take part in it, what kinds of doubts participants can have about test and/or products, and so forth. First, we contacted her to explain that we needed to do the tests; why we chose her to be the person responsible for the tests in Brazil; and the importance of this phase to the project as a whole. Then, we asked her if she wanted to take part on it, and if she agreed with our ideas. After her acceptance, we sent the printed brochures to her and instructed her about how to proceed. First, we asked her to read carefully the brochures and to fill the brochures herself to understand them. We asked her to control the time to do the tests and to take notes of problems and doubts. As soon as she finished filling the tests, we requested her to send us an email so that we could call her to plan how to proceed with the participants in Vila Rosário.

The volunteer wanted to know our ideas about the test first. We explained that we were thinking about giving the two brochures for each participant. We told her that we needed her to take notes about the participants' questions if they were connected to the tests and the products, about any important discussions that could happen among the participants, and about anything else she thinks might be important for us. We asked her to take photos of the tests as well. We explained again how important the tests are; as she had the brochures with her by now, we explained how we intended to treat the results and how the outcomes from the tests could affect the designs.

After these explanations, she agreed with the procedures. She said that the tests are easy to fill and the vocabulary utilized is familiar to the inhabitants of Vila Rosário. She explained that she would need one day to do the tests with people in Vila Rosário

and that she would use Wednesday to do it, as it was the day of workshops and meetings at the Ambulatory. Friday mornings, on the other hand, was when the stakeholders had meeting to discuss issues related to Vila Rosário. These meetings took place in the city center of Rio de Janeiro. Therefore, she wanted to apply the tests to the stakeholders on Friday. She thought the stakeholders would do the tests quickly, or else they could take them home and give back later to her. We agreed with her. She seemed to be very confident about her tasks. Another point she highlighted was that after filling the tests, she had assistants who could help her to process the results, and she knew that they would be pleased to help.

FIGURE 10.1
Participants filling the tests

FIGURE 10.2
More participants filling the tests

It was very interesting to listen to her explanation about the importance of choosing people who would be willing to take part on the tests. She thought these people needed to believe in the project, they needed to understand the importance of improving the community, and they needed to understand how our work will help in this improvement. People like these would be committed to the study, and would answer the tests sincerely. In her opinion

if people were not 100% committed to tasks, they could answer too fast, without thinking about the consequences and about how the designs can help the community. She said that people did not need to spend lots of time in filling the tests, but to think about how the products will affect Vila Rosário, more time was needed.

PARTICIPANTS

From Vila Rosário, we collected a group of participants to talk to. These people consisted mostly of Health Agents, but also of housewives and some regular workers. As the aim was mainly to create designs to assist Health Agents in their work, they were our main focus. We also wanted to have the actual “end users” of the designs as well. Table 10.1 gives a breakdown of the participants in the test.

TABLE 10.1 PARTICIPANTS IN TESTS

Name	Year of birth	Educational level	Address	Profession
Carla D’Angelo	1968	High school	Vila Rosário	Craftswoman
Clara da Silva	1966	Middle school	São Bento	Health Agent
Marluce Monteiro de Oliveira	1950	Elementary school	Parque Fluminense	Health Agent
Luiz Cláudio de Assis Ventura	1965	Middle school	Vila Rosário	Plasma TV installation mechanic

Regarding stakeholders, our idea was to study all stakeholders that were taking part on Friday's meeting, but some changes occurred. They decided to have a collective look at the tests, and then chose one of them to make one test to illustrate everyone's thoughts. Their argument for this procedure was that the person they chose knew well their views about Vila Rosário. Because of this change and the results from the stakeholder test (as I will describe below), we decided to conduct another test with the stakeholders.

The actual tests were constructed in the same way, with the same content and using the same language for all groups. In the first brochure, we organized the tests of:

- Characters
- Posters
- Tuberculosis booklet
- Nutritional questionnaire

Patrícia Prado Nascimento 1982 High school Vila São José Housewife	Neide Carvalho D'Angelo 1950 Middle school Vila Rosário Housewife	Valdéa Tomás Francisco 1962 Middle school Vila Fraternidade Housewife	
Dulcinéa Araújo dos Santos 1946 High school Parque Fluminense Health Agent	Custódia Maria Pereira da Silva 1957 High school No data Health Agent	Leila Maria Mendes da Silva 1964 Undergraduate Vila São José Health Agent	Deolinda da Silva Rodrigues 1941 Middle school No data Health Agent

—— Health Agents' uniform
—— Vila Rosário Institute's logo.[24]

We opened our brochures with a greeting. In both brochures, we finished with a "thank you" to the participants for their collaboration. We also left a blank space for them to write whatever they wanted. In the second brochure we studied the health food booklet.

TESTS

Characters

The tests started with characters that were repeated key elements in our designs. We asked Carla to invite the participants to look very carefully at the characters before reading or answering the questions. Then, she asked them to think about Vila Rosário, to remember key people at Vila Rosário, and to think about their characteristics. Then asked them to analyze the drawings and answer the questions.

The characters related to Institute Vila Rosário are explained in Figure 10.3. These were the key characters in our design work, and we wanted to make sure they are sympathetic, not threatening, and easy to associate with the IVR project. All participants from Vila Rosário answered that the Health Agent character looks like a Health Agent because she has a folder, she looks very committed to her profession, and she is captivating. All of the participants from Vila Rosário said that she reminds them of a person that lives in the community. The stakeholders, though, answered that she looks like a housewife. The main suggestion for changes was giving her sandals instead of shoes. One of them also told Carla that he believes women from Vila Rosário are thinner, have a deeper tan, and look tired.

The doctor character also passed the test. When Carla asked if he looked trustworthy, the answer was that he did because he

FIGURE 10.3
Characters related to Instituto Vila Rosário

Names suggested: Deolinda; Dona Maria; Terezinha; Josefa.

Names suggested: Dr. Herzen; Dr. Cláudio; Dr. João

resembled a physician that they know and trust. The character communicated trustfulness, reliability, and expertise. They also suggested some changes. Both groups suggested making him more similar to a local doctor everyone knows. For example, Health Agent Deolinda wrote:

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

Other characters were again built on local people, though they were typically combinations of many people rather than modelled after recognizable individuals. Figure 10.4 shows two such characters, a young man and woman. When we asked about where the boy lives, half of answers said that he lives at downtown Rio, as he is very well dressed. Another half said that he is from Vila Rosário, because he looks like one of the patients. The suggested changes were using shorts instead of pants, and wearing him into a t-shirt and slippers; also, one of the stakeholders suggested that he should be much thinner if he were to play the role of a tuberculosis patient.

The girl, on the other hand, was placed to Vila Rosário because there are a lot of teenagers "without brains" or without information about safe sex, so they get pregnant too

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I do not describe the test about the identity in this book since it is not directly related to the topic of health.

early and have to drop the school. By implication, they lose their youth and their long-term life perspective. This is common to Vila Rosário, in which women have lots of children when they are young. The changes helped us to fit her better for Vila Rosário, in which pregnant girls typically use shorts or a miniskirt, and always show their belly.

FIGURE 10.4
Characters for residents of Vila Rosário

Names suggested: Francisco; Augusto; Alessandro; Bruno; Pedro.

Names suggested: Heloisa; Valmíria; Edinalva.

Finally, we thought we needed feedback to develop further our mascot, Oscar (Figure 10.5). When we asked whether this character were a good mascot to Vila Rosário Institute and why, the feedback was critical. Just one person told that he could be a mascot because he looks like one of her patients who needs help because all he wants is a very easy life. The others were upset because he doesn't have the profile of a citizen that lives in Vila Rosário. He just wants to have an easy life. After this feedback, we decided to use him as a clown rather than turn him into a character in our stories.

FIGURE 10.5
Oscar the Mascot
Names suggested: João; Antônio; Raul; José; Rogério

Testing posters

Next, participants were invited to look very carefully at each poster before reading and answering our questions. Once more, we asked Carla to ask participants to keep their thoughts in Vila Rosário when answering the questions. We asked Health Agents and doctors to concentrate on their work at Vila Rosário Institute, and to keep in mind nutrition, tropical diseases, hygiene, and new technologies. Questions for the poster study are in Table 10.2.

We wrote an introductory paragraph for the participants, telling them to analyze each poster first and give their opinion about them afterwards. To facilitate the study, we told them we

TABLE 10.2 QUESTIONS IN POSTER STUDY (SOME OF THE POSTER'S TEST WAS DONE BEFORE THE SYMBOL REDESIGN).
Which message this poster transmits (conveys)?
Is the message in the poster clear for you? ( ) Yes ( ) No
Would you change something in the poster? If so, what changes would you make: letter type, drawings, and colors? Tell us why you would make those changes.
Looking at the poster and reading the message conveyed by it, do you feel yourself motivated to look to the Vila Rosário Institute, or the Health Agents for more information? Why?
Do you find this poster is important for the development of your community? Why? Do you think this poster is important to your work? Why?
After answering these questions about the posters' messages and images, we asked the participants to answer more general questions:
In which places of the community would you place these posters? Why?
Which posters did you like more? Why?
Which posters did you like less? Why?
Do you have ideas for new posters? Do you want to share with us? If so, feel free to draw these or write about these for us.

Cartaz 1

1) Qual a mensagem que o cartaz transmite?

2) A mensagem do cartaz está clara pra vocês? ( ) Sim ( ) Não

3) Vocês mudaria alguma coisa no cartaz? Mudariam cores, figuras, tipo de letra, desenhos? Nos digam o que vocês mudariam e nos digam o porquê mudariam.

4) Olhando para o cartaz e lendo a mensagem vocês se sentem motivados(as) a procurar o Instituto Vila Rosário, ou as agentes de saúde para mais informações? Por quê?

5) Vocês acham esse cartaz importante para a comunidade de Vila Rosário? Por quê? Vocês acham esse cartaz importante para o trabalho de vocês? Por quê?

FIGURE 10.6
Poster about personal hygiene habits

Message:
Hygiene lessons and motivation to do.

Results in brief:
The poster is important for Health Agents' work, because at Vila Rosário people have poor hygiene habits. Having objects acting as persons will stimulate the kids to understand how hygiene relates to daily activities. It is good to have the kids as target for the information. The language of the poster does communicate with families in Vila Rosário: it is not necessary to be able to read to get the message; the images already express the message. One stakeholder, however, said he thinks that the poster is not important to VR community, because the people who need to understand this information cannot read it, or will have difficulties in understanding the meaning of the message.

Cartaz 2

Tem certeza que você sabe lavar as mãos?

Venha aprender conosco!

HIGIENE = SAÚDE = VIDA!

Instituto Vila Rosário

1) Qual a mensagem que o cartaz transmite?

2) A mensagem do cartaz está clara pra vocês? ( ) Sim ( ) Não

3) Vocês mudaria alguma coisa no cartaz? Mudariam cores, figuras, tipo de letra, desenhos? Nos digam o que vocês mudariam e nos digam o porquê mudariam.

4) Olhando para o cartaz e lendo a mensagem vocês se sentem motivados(as) a procurar o Instituto Vila Rosário, ou as agentes de saúde para mais informações? Por quê?

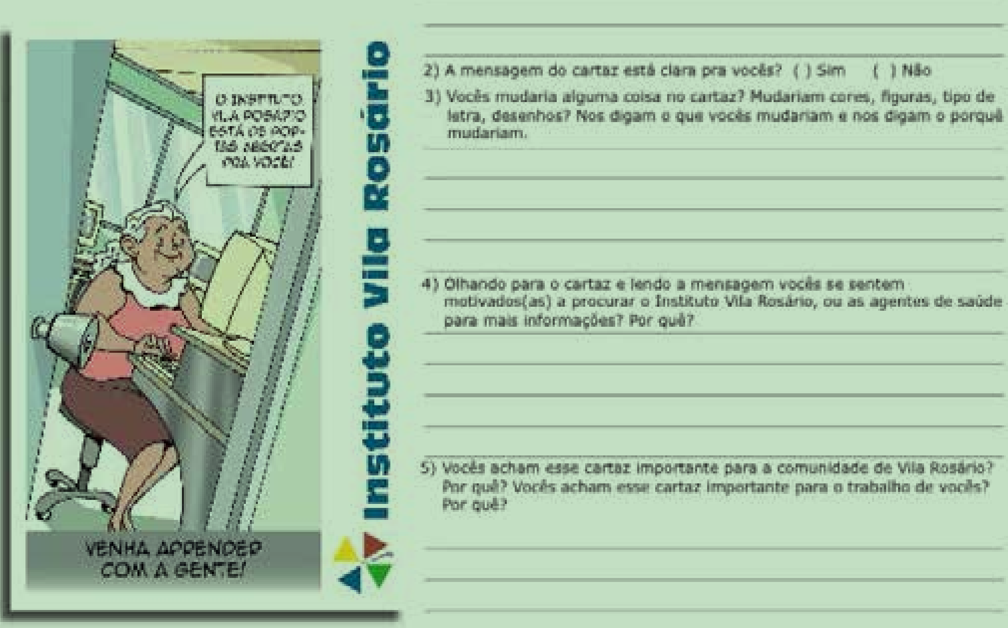
5) Vocês acham esse cartaz importante para a comunidade de Vila Rosário? Por quê? Vocês acham esse cartaz importante para o trabalho de vocês? Por quê?

FIGURE 10.7
Hygiene and its relationship to hands

Message:
The importance of hygiene and of keeping the hands clean.

Results in brief:
The poster is clear. It shows the bacteria and germs and how they get into the hands. It tells people to keep their hands clean, and that you need more than water to wash them properly. This poster reaches not only kids, but also adults.

Suggestions:
We should change the letters T and P to be more legible.



Cartaz 3

1) Qual a mensagem que o cartaz transmite?

2) A mensagem do cartaz está clara pra vocês? ( ) Sim ( ) Não

3) Vocês mudaria alguma coisa no cartaz? Mudariam cores, figuras, tipo de letra, desenhos? Nos digam o que vocês mudariam e nos digam o porquê mudariam.

4) Olhando para o cartaz e lendo a mensagem vocês se sentem motivados(as) a procurar o Instituto Vila Rosário, ou as agentes de saúde para mais informações? Por quê?

5) Vocês acham esse cartaz importante para a comunidade de Vila Rosário? Por quê? Vocês acham esse cartaz importante para o trabalho de vocês? Por quê?

FIGURE 10.8
Poster about Health Agents

Message:
The VR Institute is open to everyone and this can link and attract patients to interact better with Health Agents: if you want information to have a better life, just go to the institute.

Results in brief:
The poster is important because it transmits confidence, and it is a new way of attracting people to take part in the institute's activities. Because this poster uses an old lady in the classroom, it shows that is never late to start to learn. The poster shows that the Institute is supporting the digital inclusion.

Suggestions:
Following the same visual style, we should develop more posters showing persons learning crafts like embroidery and mosaics.

Cartaz 4

1) Qual a mensagem que o cartaz transmite?

2) A mensagem do cartaz está clara pra vocês? ( ) Sim ( ) Não

3) Vocês mudaria alguma coisa no cartaz? Mudariam cores, figuras, tipo de letra, desenhos? Nos digam o que vocês mudariam e nos digam o porquê mudariam.

4) Olhando para o cartaz e lendo a mensagem vocês se sentem motivados(as) a procurar o Instituto Vila Rosário, ou as agentes de saúde para mais informações? Por quê?

5) Vocês acham esse cartaz importante para a comunidade de Vila Rosário? Por quê? Vocês acham esse cartaz importante para o trabalho de vocês? Por quê?

FIGURE 10.9
Computer education

Message:
This poster transmits the message that people will have access to labor training through the institute; it is an invitation for everybody to use the computer.

Results in brief:
The poster is important because Vila Rosário is in the Internet age, and the computer is linking everyone easily.

Suggestions:
The poster could have women to reach out to everyone and not exclude anybody.

Cartaz 5

NÃO SE ESCONDA!

PROCURE AJUDA!

TUBERCULOSE TEM CURA!

Instituto Vila Rosário

1) Qual a mensagem que o cartaz transmite?

2) A mensagem do cartaz está clara pra vocês? ( ) Sim ( ) Não

3) Vocês mudaria alguma coisa no cartaz? Mudariam cores, figuras, tipo de letra, desenhos? Nos digam o que vocês mudariam e nos digam o porquê mudariam.

4) Olhando para o cartaz e lendo a mensagem vocês se sentem motivados(as) a procurar o Instituto Vila Rosário, ou as agentes de saúde para mais informações? Por quê?

5) Vocês acham esse cartaz importante para a comunidade de Vila Rosário? Por quê? Vocês acham esse cartaz importante para o trabalho de vocês? Por quê?

Figure 10.10
Tuberculosis has a cure

Message:
The poster shows that tuberculosis has a cure, and there are persons that care about patients.

Results in brief:
The poster clearly shows the reality. It transmits motivation to ask for help. It transmits the importance of overcoming prejudice and the importance of looking for treatment when sick.

Suggestion:
We should make another poster, using the same visual language, to describe the symptoms of tuberculosis.

had written some questions. We also said that the participants should feel free to write more about the posters, and stressed that their opinion would be listened by us later.

Previous spreads:

FIGURES 10.6–10.10
Some posters, their intended messages, the results of the tests, and suggestions gathered from tests

We also asked opinions about the posters more generally after the individual tests. The main results can be divided into two groups:

Volunteers. The most important posters are the posters related to computer training, because all kinds of education are necessary in a community so vulnerable like Vila Rosário. Here, all the posters achieved their purpose. The visual language is very clear and easy to understand.

Health Agents. Posters related to hygiene and illnesses are very important to us, and they can make a significant impact in Health Agents' work. Health Agents also asked us to develop more posters related to tuberculosis and nutrition, as there is a shortage of material on these two areas.

Health Agents also asked us to develop posters related to illnesses using children as characters. They wanted to have better communication tools to work with children. They told us that we should try to develop posters that tell children not only about hygiene, but also diseases using the same visual language. For example, we should develop a poster that tells children the symptoms of tuberculosis and shows that only 15 days after the beginning of the treatment, he is feeling better again. A poster like that would help Health Agents to manage fears associated with the disease. More specifically, they suggested us these things:

About the posters for children, we should do a set of posters: we should develop a poster to show the importance of brushing your teeth, washing your hands, and taking a shower after playing. We should explain the importance of using slippers and pyjamas, taking a shower as a habit, washing hands not only after going to the bathroom, but also before the meals, etc. Health Agents needed to approach the kids, and the posters are enjoyable to them, thus assisting in this problem. Children and old people are very important persons to be addressed, but we should keep in mind that they are more vulnerable than adults. Health Agents also told us to redraw one of the posters. Its message was not clear and it had little appeal. One Community Health Agent said that: "I can say that I learned with your posters as well. These give me more motivation to do my work".

The volunteers and the Community Health Agents suggested places where the posters could be placed:

— Local businesses;
— Schools;
— The ambulatory;
— Neighborhood association;
— Churches (people who are ill search comfort in faith and faith healing);
— Bars;
— Public squares;
— Pharmacies.

The last point merits some commentary. People from Vila Rosário search many kinds of alternative therapies, and self-medicate themselves. Pharmacies are good places to approach the population also for another reason. A local habit is to seek advice from the pharmacist before going to a doctor.

The tuberculosis booklet

In testing the tuberculosis booklet (Figure 10.11), we explained to the participants that we would test just the first page of the booklet. We also explained that we wanted to have their opinion about the characters and the context as well. We told them that we only have written the beginning of the story, and now we are inviting them to finish it for us. We made clear that we did this because of our fieldwork experience in Vila Rosário: Health Agents had shown us that most of the booklets they have used have drawings and stories that do not fit into Vila Rosário. To avoid a misfit like this, we needed help from the test persons. The introduction to the task is in Table 10.3.

Our instructions were partly successful. Participants did not draw any continuation to the story, but they did many suggestions we could add. Health Agents also did many suggestions about what is important from their point of view.

TABLE 10.3 INTRODUCTION TO TB BOOKLET WALKTHROUGH TESTS	In the next page of this brochure, you will find the first page of the tuberculosis booklet we have developed for Vila Rosário Institute. We have created some characters and we have colored it. We have tried to make it feel like Vila Rosário. Please analyze it carefully and say if you like it. Tell us if you will like to change something or not. Feel free to make any suggestions! We wanted to develop a booklet to help, for example, the Health Agents and the doctors from Vila Rosário to clarify the doubts of the patients. We want to use in it things familiar from Vila Rosário to make it fit as well as possible to its context. To reach our objective we need your help. You are from Vila Rosário, or you have worked with the community for a long time, so you know better than us how people speak in Vila Rosário, and what worries the residents of Vila Rosário have in relation to tuberculosis. So, if you want to write a story for us, we will love it! You can suggest a text by yourself or you can write together with other people!

People from the community just told that they like the visuals of the booklet, but they do not have knowledge about tuberculosis to continue to write the booklet. In our next text, we needed to add a question or a comment asking people to write their main questions about the illness. Because they do not have the knowledge, they can help us to build content that is more complete. One of the residents and one volunteer said they liked this approach. They thought we need to carry on developing the booklets following the style we had chosen. For them, the language of the booklets was simple enough and easy to understand.

FIGURE 10.11
Testing the first page of the TB booklet

Nutritional questionnaire and "Cartilha Alimentação Saudável" — Booklet for Healthy Eating

Another design Health Agents saw as important was the Booklet for Healthy Eating. We developed the booklet with the aid of a nutritionist, who wrote the text and asked us to illustrate it. In the test, we wanted to know whether the text is simple enough to be easy to understand. Another thing we wanted to know was whether its content helped people to ease the most common doubts inhabitants in Vila Rosário had about

balanced and nutritious food. The third thing we wanted to know was whether its visuals worked. It consisted of simple drawings and collages. Specifically, we asked the participants to tell what they liked about the booklet, what they did not like, and what they wanted to change in it. Table 10.4 contains the introduction to the test.

TABLE 10.4 QUESTIONS ABOUT NUTRITIONAL QUESTIONNAIRES AND BOOKLETS	On the next page you will see the questionnaire that we developed to facilitate a first diagnosis on the diet of the patient. We are trying to make the questionnaire simple and visual! Please, check if you like the drawings and the content of the booklet, and whether you think they are suitable to Vila Rosário. Feel free to make suggestions. Comments and suggestions are very important to improve our work.

The results of this test were clear. It was interesting and important to know that the Health Agents and residents of Vila Rosário both liked the drawings used in the booklet, and they had found that these kinds of drawing communicate very well with them. In their opinion, people will easily identify with the booklet. They could observe in a concrete example that is not necessary to have "sophisticated" drawings to organize communication efficiently. Rather, it is necessary to have the right language.

During fieldwork, the Health Agents had told that any drawings needed to be done by a proper artist to be effective. Some Health Agents also said that they wanted to draw by themselves, which we found a great idea. However, when we were in Vila Rosário, we asked Health Agents to draw some scenarios for us, they were so shy that they could not draw anything for us. This outcome forced us to change our approach; after some persuasion and practice, Health Agents felt themselves comfortable enough to draw, write down, or use body language to describe their visions to us.

Cartilha Alimentação Saudável

Nós desenvolvemos esta cartilha com a ajuda de uma nutricionista. Ela escreveu o texto e pediu que ilustrássemos! Ela quer muito saber se o texto dela está simples, fácil de entender e se esclarece a maioria das dúvidas que vocês têm em relação à alimentação saudável. Nós ilustramos a cartilha com desenhos bem simples e colagens. Veja se vocês gostam.

FIGURE 10.12
Validation of the Booklet for Healthy Eating

However, five inhabitants found the size of printed letters used in some parts of the booklet too small, making it difficult to read.

THE HELSINKI WORKSHOPS WITH A MEDICAL EXPERT

The second phase of the tests was done in Helsinki with a medical expert, who gave us feedback on the products, but even more importantly for us, about whether the content was correct. Dr Luiz Roberto Castello Branco has been working in Vila Rosário since 1999. He is a member of the deliberative board of QTROP Society (presently Instituto Vila Rosário), and the Scientific Director of Fundação Ataulpho de Paiva (FAP). His expertise proved to be very useful in making sure that our advice was consistent in the eyes of medical science.

Dr. Castello Branco came to Helsinki to spend one week with us, to verify the products' development. During this week, we ran a two-day workshop with him. The first day ran from 10 am to 4 pm, and focused on validating the lo-tech products. The second day ran from 4 pm to 8 pm, and focused on the web page.

As Koskinen (2007) explains, we are building a database and making communicating links for medical experts, and this high-tech product has its focus on members of medical community in Vila Rosário and experts involved in the project. Despite the web page prototype had been built focusing on medical experts, one of the goals of the project was digital inclusion, encouraging people to take part in the courses teaching them how to use the Web. The first group of people that we wanted to encourage to use the Web was Health Agents. To lower the barrier of using the Web, we designed the page using local knowledge and a visual language that community members could appreciate, recognize and interact with, just like we had done with our lo-tech designs.

In the workshops, the main objective was to test all of the products that we had developed. During the workshop process, we addressed a set of design questions; I wanted to know if I answered these during my design research:

— What kinds of Information Systems are going to be useful and enjoyable in Vila Rosário?
— How to create Information Systems suitable for Vila Rosário, given its specific character?
— How to distribute the key elements in the web page into a poor community with little access to computers, Internet, and mobile phones?
— How to make those information systems effective through action research and participatory design?

The workshop was registered on video and photographs. During the workshop, Dr. Castello Branco registered important information in format of notes using his personal computer. After the workshops we reviewed data together. As we decided to have yet another test with the main stakeholders, Dr. Castello Branco decided to be in charge of it. We made a copy of the material we used in the workshop and he had the idea to run the workshop showing the material and listening to the tapes.

TESTS OF REDESIGNS IN VILA ROSÁRIO

After Dr. Castello Branco went back to Brazil at Christmas week, he was able to do the validation in Brazil just in January 2008. He validated the products with Dr. Costa Neto. Other stakeholders were on vacation, and sent us the results on the third week of January.

Dr. Castello Branco pointed out the importance of being aware that, despite the importance of disseminating Instituto Vila Rosário's work, we had to consider how much of the population we could take care of. Back then, the Instituto did not have resources to expand the project as to all the population of Vila Rosário. They counted on six Health Agents only; they had one voluntary teacher of mosaic, etc. Then, using mosaic classes as example, he explained:

1 No matter if we will have 100 people interested in being
2 part of the course, the teacher does not have resources to
3 take care of all participants. We need to be realistic, thus
4 we need to be aware about limit, not to interfere in our
5 performance, not to affect the project's efficiency. We need
6 not to generate frustrations or misunderstanding, among the
7 community people.

His comment was a useful reminder about the realities of the project, and kept guiding us back to the designs, instead of making proposals to expand the project.

Tuberculosis Booklet

The tuberculosis booklet had two uses. It was planned to be of use during workshops in which persons responsible for childcare can use the content to develop games and play with children. Health Agents, on the other hand, wanted to apply the booklet content during their fieldwork as a support in explaining the main symptoms of tuberculosis and the importance of following the treatment.

According to Dr. Castello Branco, the story of the booklet is excellent and would work in these two uses. It really catches the attention of the audience and underlines the necessity of going to treatment. Also, the drawings and the colors are attractive. He suggested that as we intended to use the booklets for didactic purposes, we could make it even more effective. For example, we could highlight in the beginning the most common symptoms of tuberculosis and in the end, as Health Agents had suggested, we could make a list of the most important topics to discuss with the members of the community.

He suggested adding in the text that the youngster is getting thinner. Tuberculosis is a "consumptive illnesses": it means without the right treatment, the patients often almost like waste away by gradually getting thinner and weaker. This term is particularly applicable to tuberculosis. It is also an old fashioned term, and people in Vila Rosário know the disease by this term. Another important point is that if the patient has not looked for aid yet, he is transmitting the bacillus to other people anyway. Tuberculosis is transmitted from person to person via tiny droplets from the throat and lungs of people with the illness. This contagion

mechanism is common in Vila Rosário. Because of the stigma of having tuberculosis and lack of understanding of how it spreads, people delay looking for help all too long, and can spread the illness for months.

He also suggests continuing applying the community language for explaining the symptoms of the disease. In his opinion, we were doing this in a consistent way, using funny words that are part of their day-to-day life and that also connect well to medical terminology.

The idea of having a pregnant woman as a character was very important in his opinion. He agreed with Health Agents that they also had many young mothers at the community, and they have to clarify what tuberculosis means to them.

> "If the Health Agents asked to emphasize this issue I think you should go further and discuss more this issue."

He went on to expand. For example, he suggested that we could explain that tuberculosis is not transmitted to the fetus; it does not have a transmission mechanism for the placenta. However, there is a high likelihood that the baby contracts the bacillus after the birth, making this situation more preoccupying than pregnancy. When a woman is pregnant, she has a discrete immunodeficiency, and as a result, she is more susceptible to some illnesses. In the story in the booklet, the fiancé may have tuberculosis. As the mother and the baby are in constant contact with each other, the mother can easily transmit tuberculosis to the little one. As vaccination diminishes the risk of contagion, we could stress the importance of the vaccination to the mother. The vaccination is done for babies when they are 30 days or younger. It is a part of the national program of immunization. As Dr. Castello Branco added, it is of course important for the mother to get treatment as well.

FIGURES 10.13–10.16.
Testing the designs with
Dr. Luiz Roberto Castello Branco.

Dr. Castello Branco liked our idea of using the booklet as a support material to create games for the kids, as well as for teaching the basics of tuberculosis to the participants of IVR workshops. He also liked the idea of targeting the booklets for children while the mothers are taking part on the workshops, as well as when the Health Agents are visiting the patients. It would be important to distribute the booklets to schools where they could be used as didactic material, too.

Comments on characters

Dr. Castello Branco also commented on other aspects of our designs, including the characters. To give one example of his comments and how they reshaped our designs, we can look at one of the characters, Dr. Claudio (see Figure 10.3). As Dr. Castello Branco noted to us, Dr. Claudio was one of the first persons to "see" the community. "For the Health Agents, as you could identify in your fieldwork, Claudio is one of the most trustful person they know. He is the person that is a symbol of citizenship for them".

Dr. Castello Branco suggested that we could develop other themes for the booklet as well. Using other interesting characters that are connected to Vila Rosário's reality can be a further reason for enjoying the booklets. For example, we could introduce a football player.

Brainstorming with Dr. Castello Branco

Soccer is an important sport in Brazil and it reaches all social strata. His idea was to have as a central character a footballer from the region. The player was born there and grew up there. He became a great footballer, and was discovered during a game from Instituto Vila Rosário Sport Club. After a period of success in his career he discovered that he got tuberculosis – this would show that everyone can be ill, no matter how well-off and famous they may be. He follows the treatment and is completely recovered; here we would need to underline the importance of following the treatment exactly. This kind of story motivates people using the most important of the sports. To finish the booklet in a grand style, Dr. Castello Branco suggested a scenario in which the player is going to have his first important game after the illness. During the game he scores and offers it to his son who is on the grandstand dressing a t-shirt from Vila Rosário Football Club – his father's first Club. This part would be very emotional to people. They would be proud about their community, and would love the story so much that they would want to spread it.

However, football is a sport connected to boys and men.[25] Dr. Castello Branco also suggested us to create a story about a woman, who has an important participation in the community life. For example, she could be a cook. During fieldwork, we identified the importance of some women, especially some grandmothers, as sources of knowledge and wisdom. Through stories, songs, recipes, care of the house, and so forth, these women are responsible for disseminating the community's culture. In our new story, a woman loves to cook for the children. She cooks in her house, and she has tons of experience about kitchen garden. The Health Agents told the story about this woman to Costa Neto, and the woman is contracted by IVR. After one year of a successful work, she got tuberculosis. She needed to stop her work, but after fifteen days of strict treatment, she started to feel better. She was still worried about working as a cook, but she told the stakeholders she needed to have something to do, to feel herself more important. The stakeholders suggested that she should try one of the workshops they have at IVR. The woman decided to enroll herself in mosaics and was very happy with her new work. This was a good story that shows if someone follows the treatment, after a fairly short period of time, she can be reintegrated to the community.

At this moment, the test had become a brainstorming session. Dr. Castello Branco and us started to develop more stories and we also started to think together about ways of reaching all the audiences we intended to reach. We saw the booklets were important, especially after the Health Agents' feedback. We felt we had good designs, and decided to ask for more ideas to help them in their work. We remembered an issue that Leila and Dulcineia had talked with Dr. Castello Branco on the difficulty of approaching the "rich ones" at Vila Rosário. Dr. Castello Branco agreed that this point is important

25
Women used to be connected as well, but more connected during the World Cup – we have had the experience during our field work. We arrived in Brazil during the World Cup and nobody wants to have workshops on match days. It was a good example of the importance of football for Vila Rosário's community, and a reminder of how we could use the topic in our work.

because, as Health Agents had told us, these people think that because they can afford a health insurance, more goods, and more information, they will not get sick. The stigma of being sick would also hurt them more than the truly poor.

We were reminded about soap operas as an important medium. We had used soap operas in developing our probes packages (specifically, postcards) and they had worked very well. With references to soap operas, we could promote the discussion of important problems in Brazilian culture, without stigmatization and taboos: people feel themselves free to talk about all issues related to the screen life of the characters.

Building on this thought, we decided to create a story about a TV actor with tuberculosis. The person is acting in a very popular novel, in which he is the main character. Suddenly, he disappears. People start to talk about this situation, gossip and guesses start to circulate all around the town. After three weeks, he gives a national interview. Everybody in Brazil stops to watch the interview on TV. The person gives a moving declaration about having tuberculosis. Having an actor as a main character, people will accept the story. We can talk about stigmatization, shame, vulnerability, and other myths about the disease through this character. When the actor is speaking to the public, he is proud of being cured. Being able to speak about this issue on a national broadcast is an important stimulation for people looking for help. In Vila Rosário, the story would help people to listen to Health Agents. Says Dr. Castello Branco:

> "The physical characteristics, the way people speak, the body language, the way the community members dress etc. You really portrayed life in Vila Rosário. You have caught the essence of the people that are part of the Institute Vila Rosário as well."

Nutrition

Posters. Dr. Castello Branco liked our ideas for posters, but he suggested us to go further with the idea to make it clear what is forbidden or what can be eaten in especial occasions, for example. The idea was to use a red mark on the unhealthy meals. Dr. Castello Branco suggested us to make the posters easily understandable to the people. He underlined that the idea of developing posters based on pictures from the community is strong and works very well. In fact, he corroborated the results from tests with Health Agents and the volunteers.

However, Dr. Castello Branco suggested making the characters funnier. In his opinion, the characters needed to have expressive faces in the manner of entertainers. Exaggerated facial expressions can motivate the children to get better engaged with the characters; to catch the attention of children, we should develop stories that stimulate and develop their creativity. Dr. Castello Branco also suggested us to use animals as characters, and suggested using the Food Pyramid in the posters. According to him, the pyramid is easy enough, and is an excellent guide to healthy eating. He suggests us to ask the nutritionist about it.

Dr. Castello Branco then said that the first years of the child's life are the most important years for their growth. Therefore, it is vital that small children have nutritionally rich diets. What we could see in Vila Rosário was that a part of the adult population has learning difficulties; a part of the reason was that they had not been fed in a right way in infancy. Nutrition is one of the pillars of having good community health. Dr. Castello Branco made it clear that he was not excluding other factors like education that contribute to this issue as well, but that he just stressed that if in a community a great part of the population suffered from malnutrition at early age, this situation will have an

impact on the central nervous system. This results in problems in development and later, in learning abilities.

Health food booklet. Dr. Castello Branco was positive about the idea of using a new way of drawing the booklet. He also liked the format and the colors. About the content, he said he liked the language and the content. He asked about the results we had in tests with the community.

> "In these results that I brought from Brazil for you, what had the agents and the inhabitants said about the booklet? I want to know more about their opinion because these results are the most important results for the project. My opinion as a specialist is important, but they know the context in a deeper way".

We explained that Health Agents, volunteers and people from community have said that it is important that the major focus of the booklet was on pregnant women, nursing mothers, children from birth to pre-school, mothers, and grandmothers (some grandmothers were important guardians of culture in Vila Rosário, sharing their experience with children). After the test with the Health Agents, we also saw that the booklet had improved Health Agents' knowledge of nutrition as well. They had explained to us that they had some doubts regarding a few topics in the booklet, but the booklet had helped them in clarifying these doubts. One Health Agent told us:

> "Some topics you discuss in the booklet, I had no doubt about these because I had no idea about that issue. I never thought about these, so it is impossible to have doubt about something you even have no idea about".

She told that the booklet is a great material for her own learning. Marluce, another Health Agent, told us during the fieldwork:

"You always have to remember that we [Health Agents] are part of the community and, like them, we have, many times, the same doubts people from Vila Rosário have. We face the same difficulties of the people of the community. Have it clear on your minds while you are developing the products".

The inhabitants had said that they wanted to have one booklet at home to guide them in preparing their meals.

Dr. Castello Branco next suggested to change the black color used as the background in one of the booklets. In his opinion, it can make reading of the booklet tiring. He suggests trying white instead. He asked if some of the others have said something related to the color of the booklet, or was it just he who had this question. We told him that one person had a similar opinion, but this person had complained about the vivid colors applied on the booklet as a whole. Dr. Castello Branco stressed that vivid colors are important to highlight the content of the booklet. Also, vivid colors are important to underline different groups of food.

He also pointed out several things we should check in finishing the booklet: acknowledgements, illustrations, partnerships, and support. Most importantly, we should not forget to express our gratitude to Health Agents and other volunteers, and we should cite their names. He believes that this gesture is very important for them. The Health Agents and volunteers will feel themselves useful and important in being a part of the research process.

Nutritional workshops. This part of the test started with an explanation about the idea to use the kitchen garden and the kitchen to run nutrition workshops. The idea was that students could be given examples of healthy nutritional habits through the garden. Taking part in the nutrition workshop would help to raise the inhabitants' ecological and nutritional consciousness.

Yet another aim was to improve the appreciation of human relationships and social responsibility, as these were identified in our fieldwork as important cultural values in the community.

In the kitchen garden, the students had an opportunity to grow plants from seeds and seedlings. They could use this moment to learn how to prepare the soil, how to plan a kitchen garden, and how to select plants good to the soil. They could also learn about correct times to cultivate various crops, and about the nutritional aspects of each plant. As Dr. Costa Neto stressed, they could apply their experience in their homes, as kitchen gardens do not need a lot of space.

The idea was also to go to the supermarket or to the markets with the students. The aim was to teach them what kinds of products are good to buy; they would learn how to understand the information on labels and on the packages, and how to choose nutrition-rich fruits and vegetables.

In the kitchen, they should learn how to clean and prepare foods. For example, they needed to understand that bacteria can spread from one food to another, so if they were cutting chicken, they had to clean the knife and the chopping board before they started preparing other foods. The aim was to teach them how to prepare a weekly menu and how a supermarket list is connected to diet. They would also learn about hygiene: the importance of having personal hygiene, for example, about the importance of hand-washing after preparing raw chicken. Finally, they would learn about environment hygiene and food hygiene to avoid or minimize the occurrences of food borne illnesses. They would also get a recipe book with illustrations and nutritional information of various staples.

The second part of the "Nutritional Workshop" was training the participants to keep an herb garden. The students were to learn about three different types of herbs.

1) Medicinal herbs. An herb garden would provide a good opportunity to demonstrate how to grow and use herbs with medicinal value. During the fieldwork, I noted that there was a culture of using some herbs as medicines, especially among older ladies. This is important knowledge, but it is also important to show that these herbs need to be used carefully. Some herbs are harmless but others can be dangerous if consumed in excess;
2) Aromatic Herbs;
3) Culinary Herbs.

Dr. Castello Branco liked the idea of the workshops and the issues to be approached. He suggested starting to develop the workshops with the nutritionist. I explained to him the idea of developing movies with people from the community, to illustrate the issues to be approached during the workshops. We had used the example of Health Agent Maria do Rosário, who was the best example of a local woman who wanted to transmit her norms and values to the community.

Dr. Castello Branco considered making a video a very good idea; he agreed with us that making films with the inhabitants would show them that Marcelo and I respect their culture and see their skills as a fundamental part to be integrated into the program. He said that social responsibility is a great part of the Health Agents' values. He thinks that integrating the nutritionist vision with the Health Agents' point of view, as well as with our view as designers, would be an important step in motivating inhabitants to take part in the workshops. Watching movies can be inspirational, after all.

Nutritional questionnaire. The Nutritional questionnaire came to our agenda from Health Agents. According to them, it was fundamental to understand the inhabitants' diet. They had

FIGURE 10.17
A family in need of nutritional information

recognized during their work that what the people ate in their daily life, which foods they preferred, which foods they could afford, and so forth, can have many consequences on their work. Health Agents also stated that as the majority of the population have difficulties communicating with others, it is very difficult to do the diet inquiry. Based on their experiences, they said that communication by images is the best way to have better and more reliable results from the community. Building on these experiences, Marcelo and I went on to develop this idea further.

One point we considered was developing a questionnaire around a sequence of images related to stories, to make it more inspirational and more understandable to the inhabitants. During the fieldwork, we had seen that by building stories on the inhabitants' experiences, and by connecting these to their reality

helped them to better understand the meanings of the images. To develop the booklets, this observation was very important for us, as we went deeper in local stories, myths, legends, songs, pictures, and movies.

The nutritional questionnaire was made as an initial proposal, which was to be tested with Health Agents, volunteers, doctors and by some inhabitants, and later by a nutritionist. We had a lot of stuff to build on. The probes gave us many hints about Health Agents and what their families ate. During the fieldwork, observations, interviews, and stories gave us an illustrative panorama of what the community members could afford, what they liked to eat, what a healthy diet means for them, and so forth. It was also possible to analyze Health Agents, the volunteers, and the specialists' perception about this issue and understand their habits related to eating.

Based on these data, it was possible to understand the key issues to be approached on the questionnaire. The idea is that the Health Agents administered the questionnaire in the first contact with patient, and also left the questionnaire with the patient to be filled during the week. This consideration of leaving questionnaires to be filled by the patient was another tip that came from Health Agents. They explained that it is important to understand the food cycle during the whole week because people do not have the same habits every day.

Dr. Castello Branco also reminded us that people had the custom of having a better meal during the weekends, and these changes in feeding are important to be considered. He suggested that we should prepare the questionnaire with a nutritionist. He explained that nutritionists have different approaches depending on the patient. For example, the nutritional evaluation can be done in 24 hours, 48 hours, 72 hours or one week depending on the patient's case and her way of life. Dr. Castello Branco

reminds us that it is important to have personal data and time-related data in the questionnaire, because it can be used as control variables.

We argued that our intention is to develop different questionnaires, with different contents for the first approach of the patient and the follow up of the diagnosis. We also explained that the measures as "one glass" of water were chosen by us to have a better understanding of measures used by Health Agents'. The nutritionist had underlined the problem related to measures; for example, one glass of water depends on the kind of glass. Some inhabitants have no drinking glasses and use cans or plastic bottles. We also needed to know if the people have drank all the water or just half of the glass. These were just some examples that can change and affect the diagnosis. At this stage, our idea was to test the standards of Health Agents, the volunteers, the community's members and the specialists.

The questionnaire needed to approach diet holistically. To develop the questionnaire, we had to keep in mind that its utility is based on the specialists' objectives and also on the Health Agents' purposes. For example, the nutritionist had underlined that the way people cook the foods can change their nutritional value. Therefore, it is important to know how people choose foods, how and when they buy food ingredients, and so forth.

To take in account this holistic demand, we started to develop products like movies and games, and the workshops to be included in the nutritional diagnosis. We could not have all the issues approached in just one questionnaire. We had identified the need to develop integrated actions, having respect for the local culture. We had to consider for example the educational level of the people in the community. In addition, one of the Health Agents highlighted that she could not take notes of all the nutritional habits of patients. People sometimes told stories

to illustrate their habits; some inhabitants showed the content of their refrigerator or cabinets to illustrate their habits; sometimes they invited the Health Agents to the table. In these situations, the Health Agents said they couldn't write things down. They said that we needed to develop an approach not only for diagnosis, but also for educating and informing people about the importance of the food. They told that the majority of the inhabitants of Vila Rosário have no idea of the consequences of malnutrition. The majority of the inhabitants bought cheap rather than nutritious foods. The nutritionist also said that people often buy more expensive food with less quality because they, for example, do not know which fruits are seasonal and therefore cheap.

Designs for hygiene

The final thing we tested in our study were designs focusing on hygiene. Again, the feedback from the tests was approving. The designs were thought to be clear, concise and vivid enough to show why it is important to be clean. One issue that came up in our tests was color, though. Health Agents had pointed out white as one good color for hygiene. To them, white is a color that always seems to be clean. They used the example of their clothes: if they are wearing a white t-shirt it needed to be really white, without any spot, well ironed, well cared for. In their opinion, this is a very good example of being hygienic. But using the same example they explained that if a person is wearing a total white outfit she will need to add some color not to be "boring." The person may need to add a necklace, for example; or she may need to have a nice tan to catch the attention of others, which is not good in terms of health. In a similar way, Dr. Castello Branco argued that white is not the best color if we want to talk about hygiene.

At the end Marcelo and I decided with the Health Agents that blue is the best color to talk about hygiene. This is the color of clean water, freshness, and infinity. They related blue color to the blue skies, and to the water of the oceans. I tried to argue with Marcelo that if blue has these characteristics, it could be better suited to ecology, but Health Agents firmly stated that for them, the meaning of this color goes beyond nature, even though their examples came from nature. It is applicable to community's life as well. One of the participants gave a convincing example: the water of the oceans used to be blue and... It is about tranquillity, peace, and quietness. However, if there are huge waves in the ocean, it will have a mixture of colors. People can perceive its power and think it is getting "angry." When blue ends and the white or maybe gray becomes dominant, people start to fear the ocean and it gets blue again. When a disaster affects the beach, water becomes dark and dirty, and people cannot enjoy the refreshing waters of the ocean.

It is the same story with hygiene, Health Agents argued. If a house is predominantly blue, the family feels comfortable, calm, and secure. On the other hand, if the house starts to change from blue to grey, the person will start to be vulnerable to illness. Although this description of the "personality" of the colors was mystical for us, the metaphoric sense seemed reasonable, and in the absence of other arguments, we decided to associate blue with hygiene.

11

Potentials: Streamlining and Testing the Program in Namibia

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After implementing and studying our designs in Vila Rosário, we knew that the program worked and was useful for Health Agents. Our designs targeted some of the main concerns of Health Agents, doctors and families in the area. They also helped Health Agents to do their work better by giving them visual aids that helped them to better explain issues on health, hygiene and nutrition to local population. Health Agents and locals could make sense of the designs, and found them attractive enough to be useful. The program had some success, at least initially.

Our design program, next, faced two problems of another kind. The first was what can be called transferability. We knew that the program worked in Vila Rosário, but it is only one place.

We did not know whether the program was transferable to other places and if it was, what kinds of changes it needed. The second problem was the amount of work we put into developing the approach. In developing a design program, it is perfectly fine to use three years for thinking, research, design and reflection. If the program is to have any value in real world, this is not the case. The program has to be streamlined so that it can be done in a few weeks, or at maximum in a few months.

To address these two problems, we wanted to repeat our study in another place. Rio de Janeiro offered several possibilities, but we wanted to have a test case in another culture. In creating a program, we thought, it was better to test it in a place that faced many of the same problems as Vila Rosário, but was different visually, in terms of community, and culture. An opportunity came to us through our network in Helsinki through Satu Miettinen, a Finnish designer who at that time was working on her PhD in Namibia. She was running a series of workshops in that country, called *Potentials*. For us, Namibia offered a good test case: it was suitably similar to Vila Rosário in terms of public health, climate and poverty, but it was also from another continent, with a different past, and with different sensibilities what comes to visual and cultural patterns.

In this chapter I will describe the workshop we ran in Namibia with Miettinen, the World Design Research Group of UIAH[26], and the group of Pambili[27]. The chapter starts

26
World Design Research Group consisted of a few (then) PhD students who were interested in designing for countries outside the traditional realm of design, which is Western Europe and North America. Most of its members focused on developing countries. See Chapter 1 for more details.

27
Pambili is an association vision to encourage individuals and groups to become self- sustainable through craft design. http://www.globewomen.org/summit/2009/Speeches/Web%20PDFs/Melanie%20Harteveld%20Becker.pdf

with a brief introduction about the general objectives of the workshop. Then we explain our main objectives in conducting the workshop. Further on, I will describe the methods we applied and the stages of the workshop. After that, I will discuss how our methods developed in Vila Rosário worked in Windhoek. Finally, the chapter reflects on the essential concepts related to social design intervention. The questions addressed in this chapter are: does the design process we developed in Vila Rosário work in another place? And can we know how it should be changed?

POTENTIALS: THE NAMIBIA WORKSHOPS

Potentials 2 project was developed by Namibian Pambili Association with the World Design Research Group of the University of Art and Design Helsinki (UIAH). The idea was to focus the workshop on challenges on social design and on finding new teaching models to improve the Namibian capabilities in design and design research (see Miettinen, 2007).

The second *potentials* interactive workshop was held in Windhoek between the 9th and the 11th of July 2007. The workshop "Design Your Action" was built around seven action stations. Each action station introduced themes through case studies. In our case, Marcelo and I described the Vila Rosário case. The idea of the workshop was to enforce the importance of empathic and participatory design as a potential key approach in social design. After the workshop, we organized an exhibition to present the outcomes of the workshop. The exhibition first took place in Windhoek and then in Helsinki. In Helsinki the exhibition happened during the Fashion Fair 2007. The central idea of the *potentials 2* workshop was to demonstrate that there is a relationship between design policy and design action.

In this specific case, the action was a design process of doing interventions that dealt with several issues in social design (Miettinen, 2007).

When we had run a design Intervention in Vila Rosário, we had focused on the development and comprehension of visual elements, which we used on the designs we developed in Vila Rosário.

As I said earlier, our main aims in *potentials 2* were to test whether the methods and processes we developed in Vila Rosário work in another context, and to understand the implications of cultural context to our approach. Specifically, we wanted to understand whether the colors and symbols we had chosen in Vila Rosário made sense in Namibia, and whether they were acceptable there. We studied two design elements in these workshops:

1) Colors. Our first interest was visual code: cultural perception of colors. The second interest was color as format (as a pattern), and the third color as a directional entity in navigation.
2) Graphical symbols. First, we were interested in the familiarity of symbols, i.e. the participants' knowledge and perception about words and categories and things that we had used to represent contents. Second, we wanted to learn about the participants' ability to understand the symbols: whether they were legible and easily readable; simple and easily reproduced in different media; and consistent.

These questions were particularly relevant for the website, as the long term aim of the stakeholders of the Institute Vila Rosário was to transform it into an international portal. The short term objective of the workshop, then, was to develop a web page to improve interaction between community's members, doctors, researchers, and volunteers in Namibia.

SELECTING SYMBOLS FROM VILA ROSÁRIO FOR NAMIBIA

Several methods and stages were used to prepare the workshop material and to run the workshop. Table 11.1 shows the main stages of the process. After a fairly long preparation period in Helsinki, we designed the workshops and did them in Namibia. Just as the preparation stage, the aftermath was prolonged as well, consisting of an exhibition organized in Namibia for feedback, data analysis in Helsinki, and a final exhibition in Helsinki.

The actual workshops started with a study in which we pre-selected symbols to be used with the Pambili group. After this phase we organized the actual workshops in which we first worked together to design the symbols for the products, and then went into detail designs.

Testing symbols

To understand the symbols and colors as design elements in our action station, we used many kinds of data from Vila Rosário. The most important data were photos taken by Health Agents and other people from the community; and interviews we had done with specialists, Health Agents, and people from Vila Rosário. We also used the Instituto Vila Rosário web page as a benchmark.

Following this procedure, we selected images to be tested in our workshop. First, we drew the images in a black and white, and we standardized all the images by putting them on a white background. Our aim was to make the images more visible and legible, with fewer elements that could interfere on their comprehensibility. After this procedure, however, we decided to keep colors in some icons to understand more about the influence and the power of the colors on the symbols.

TABLE 11.1 POSITIONS: WORKSHOPS IN NAMIBIA

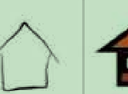
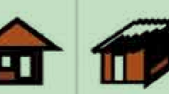
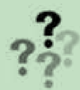
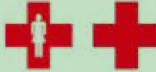
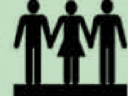
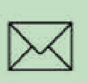
- Preparing the workshop using data from IVR
    - Preliminary mapping (Rio de Janeiro)
        - Community Health Agents – CHA, and Community Member – CM's photos
        - Interviewing Specialists, CM and CHA
        - Benchmark (Helsinki)
    - Designing Icons (Helsinki)
        - Systematizing data
        - Transforming in Black & White symbols
        - Identifying Patterns
        - Icons in Colors
    - Pre-selection test (Helsinki)
        - Choosing categories and symbols
- Developing Panel for our Action Station: Design Intervention in Vila Rosário (Helsinki)
- Namibian Workshop (Namibia)
    - First Contact
        - Introducing tutors
        - Forming groups
        - Introducing groups
            - Knowing participants
            - Expectations (What they think/ feel about our research)
    - Production Method
        - Presenting the concepts to the participants;
        - Some groups thinking aloud;
        - Asking them to draw ideas about the concepts;
            - (We didn't show the icons from IVR)
    - Comprehension Test for Vila Rosário symbols and colors
    - Hierarchical organization of symbols and colors
    - Inviting participants to develop the IVR web page (just symbols and colors)
- Namibia Exhibition (Design Your Action)
- Analysing data from the Workshop (Helsinki)
- Systematization of the data
- Results to be applied in IVR's web page
- Helsinki Exhibition – Fashion Fair 2007

The symbol to represent Health Agents, for example, had the cross in red; the house drawing based on the picture taken by Health Agent was brown, like in reality. We had to remind our participants in Namibia that many participants in Vila Rosário had difficulties in reading. For this reason, we told, many of our interviewees in Vila Rosário had always stressed the need for designing elements that were not based on written language only. They underlined the importance of images for understanding, and for this reason, images from Vila Rosário were specific to that location and not necessarily understandable in another country. After this preparation work, we went on to administer our pre-selection test.

FIGURE 11.1
Symbol categories considered for the workshop, and categories studied

Selecting symbol categories for the workshop. At the beginning of the workshop, we wanted to study nine symbol categories, but due to the time we had to run the workshop we just approached six of these (Figure 11.1). Due to the time restrictions, we had chosen six symbol categories for closer tests. In the studies conducted by Zwaga (1989), Brugger (1994), and Formiga (2002), seven such referents were used. This figure, we thought, was arbitrary. As our aim was to use symbols as an inspirational start in the workshop, we restricted ourselves to six symbol categories that also fit our schedule better. We chose the categories based on the feedback we received from Vila Rosário, as I explain next.

The set of symbols applied in the workshop contain a selection of four symbols for six referents design to be used on Vila Rosário's web page. The referents we chose are in squares in Figure 11.1 above. In selecting symbols, we did a pilot test in Helsinki with teachers, researchers and students from UIAH.

Referent	Function	
Home	to Start the visit	 
Craft	to know about Workshop and products	
Frequently Asked Questions	where you find answers to the most common doubts	
Health Agents	to give access to private areas	
Vila Rosário´s Map	to show directions to reach Vila Rosario	
Search	to search content inside the website	
Partners	to know about who support the project	
Training	to give access to training area	
Contact	to allow user to get in touch with people involved in the project	

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FIRST CATEGORY (REFERENT): HOME

In Vila Rosário, home is the space where you have your family with you. You share your home space with people you like, people you care about. It is a space where you have control; you are responsible for your behavior and your acts. When someone approaches your home, they will do it through the main door, and they enter an important place. Home is a place where you can do things together with your family and friends; it is also a place in which you can do meetings to develop your community.

> "As we are from a marginalized community sometimes we feel that we are excluded from the right of decision about our city or even worse, about the development of our own community. So, at least when I am at home I know I can make decisions."

Based on this quotation and the feedbacks from Vila Rosário, we decided to treat home as an important category. Home is a word that has a deep meaning in the community, and it was to be important to have a house as metaphor to give significance to the main page of Vila Rosário web page.

In our design, we thought about talking about Main Page instead of Home Page, but rejected this idea after feedback from the members of the community. They told us that people in Vila Rosário would like the idea to being transported into their home on the main page of the site. They want to feel as they are in their home and they want to have the safe feeling of comfort and security. Thus, using a house as a base metaphor on the main page makes emotional sense. As the majority has no access to computers, they need some "tangible" ideas to make them feel more secure in the virtual world. Therefore, it is good to have a strong metaphor like this on the main page. It is also a place where people can find the most important bits of information; and a place to which people come back again and again.

To choose the other categories to be approached in the workshop we followed the same idea: we tried to find the main aspect in their real life that would be good to be placed in the virtual world.

HEALTH AGENTS

Health Agents were considered as the key persons of the project by the community and the specialists involved in the Vila Rosário project. When we think about the Vila Rosário project, we need to think about them. They are persons that asked us to design the web page thinking about their work with the community, and they

asked us to develop the page as an efficient media to improve the communication in the community. Also, they did these claims as Health Agents, but also as community members.

Therefore, the icon for Health Agents was going be an important part of our web page. When the community needs to interact with doctors or with outsiders, they frequently asked the Health Agents to help.

> "When I need something, specially related to health, I often asked their advice or ask their help to orientate me. If I need to go to some hospital I frequently ask them to go with me."

> "If I need to find some information in the computer (meaning web page) I will try to find the Health Agent area there! Probably I will find some advice related to health in this section! I am thinking like this because they are the persons that are trying to help us to improve our community healthy... am I right?"

Based on these quotations and the feedbacks I described above, we decided the Health Agent is an important category to be approached. Health Agents need a special icon that can be representative of their importance in the community.

MAP

This was a challenge for us because of the different representations of a map and its function. The map in Vila Rosário, as explained in Chapter 9, can be an important device for tracking the contagion pattern and the geography of illness. So, we needed to have a satellite map said the doctors, and also a way in which Health Agents can enter information to it. Outsiders, in their part, wanted to have a map to find Vila Rosário. To reach destination, they need references like landmarks. As the community is difficult to find, we needed to find visual elements people are already familiar with when travelling into the community.

So, in this case we wanted to have three different maps on the web page. In Namibia, we wanted to learn what kinds of maps can be representative on the web page. At the same time, we wanted to learn about descriptions that could be used in maps as symbolic representations.

SEARCH

The concept of search proved to be difficult to visualize. Based on the answers we received, we clearly saw that for most people,

it is a challenging word that is ambiguous and imprecise. Most people asked us to think about search as a synonym to looking for someone or something. When we asked people, most people responded with a gesture: they touched their forehead with their hands and looked to the horizon, meaning they are exploring the horizon to find something. The doctors, and specialists, on the other hand, who had had contact with devices and computers drew binoculars, lenses, and magnifiers.

CONTACT

We chose this word because on our web page we needed to make a drawing to represent different kinds of contacts to Vila Rosário Institute: by phone, email and by the post office.

FREQUENTLY ASKED QUESTIONS (FAQ)

This was something that made little sense to people in Vila Rosário. As the majority had not had contact with computers, they could not understand a category named "Frequently Asked Questions." We had to find a way around this problem by finding similar practices from their everyday life. For example, we asked Health Agents if they had a kind of archive where they write down and keep the most common doubts of patients and other people. One of the Health Agents reminded us:

> "As we told you during the interview about the importance of the booklets to our work, and what kind of content fits in our reality, we know the common doubts the patients, their families, their friends and other people usually have... I have all of it in my mind, my personal archive. These doubts are part of our day-by-day and we are always explaining the same thing to the people. That's why I think these contents need to be in the booklet!"

We agreed with her, and told her that we absolutely know that they had their "personal archives." That is why we needed to have all the content (or at least the majority) on the web page. At this moment, one interesting point for us was to see that despite their anxiety of having a web page and using it, they always try to remind us about the importance of lo-tech solutions like booklets. Even when they started to feel themselves more confident in using the computer and in having a web page as a support for their work, they still felt more comfortable with booklets, posters, and so on.

As we had to explain the function of the referent using examples, we were afraid that our perception would influence their answers.

For example, we compared this symbol to “archive.” To our surprise the majority made a connection between FAQ and the question mark, or the FAQ and an expression of doubt. We thought the reason for this result was that these are more related to their reality.

THE NAMIBIA WORKSHOPS

In Namibia, 35 persons took part in our workshop. Regarding the educational level of the participants, there was a marked difference to Vila Rosário: the university level was prevailing in Namibia. The number of female and male participants was balanced (16 women and 19 men).

The beginning of the workshop

As soon as all the participants arrived at Studio *77*, where the workshop took place, the participants were invited to come inside and take a look around the space. After about ten minute, Melaine, *Pambili* coordinator and one of the tutors, asked the participants to come outside and take a seat. It was a beautiful sunny day, and as we did the workshop in the Winter on the Southern Hemisphere, it was a great idea to site outside to start the proceedings.

First, Melaine gave a speech and introduced the tutors. Then, she asked the participants to separate themselves in groups of 5 persons. They were free to choose the groups according to their wishes (Figure 11.2–11.3). They got 30 minutes to talk about their objectives and expectations about the workshop, and they could share some experiences related to their own work or study. The idea was to make them feel more confident in taking part in the workshop, and at the same time to learn to know each other before we started the action stations.

FIGURE 11.2
Organizing for the workshop

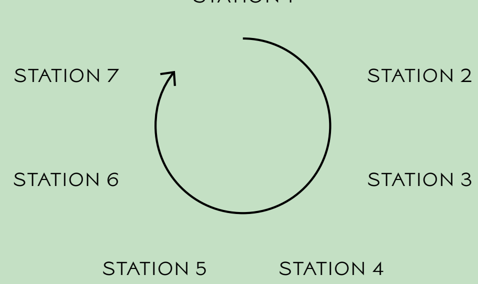
FIGURE 11.3
The workshop begins

After they had formed the groups, each group received a number and was asked to choose a leader. The leader had to present the whole group and to explain to the tutors and to the other groups what the group expected from the workshop.

This phase was really interesting because participants could share their backgrounds and expectations with us. To take their expectations and their ideas into account, we adapted our workshop process to try to meet the participants' objectives. Even though we developed a flexible approach, we could do this without losing our focus.

After this moment, the participants were asked to walk around the workshop place once more, but this time reading the panels from each action station. The aim here was to give them a better understanding about the stations.

FIGURE 11.4
The organization of the workshop space in Studio 77



The space was organized in such a way that all the groups could rotate and take part in all seven actions (Figure 11.4). In our station we started our approach with group 6 followed by groups 5, 4, 3, 2, 1 and 7, in this order.

Warming-up

In the next stage of our work, we utilized Formiga's (2002) approach as a starting point for us. In her work, she follows the production method of Krampen (1969). The method developed by Krampen allowed us to elicit information by getting people to produce drawings of verbal concepts presented to them. This approach had been useful in improving the design of the icons of the Vila Rosário web page. For this reason, we decided to use the same approach. It had provided us with important and useful information for analyzing icons comprehensibility before, and it had given directions for drawing new icons. It had also helped us to analyze the composition of icons building on community perception, not our own. In the spirit of Freire, it directly involved community members in our design process.

We followed this procedure: we started our workshop by asking participants to tell us what they thought about our work, as they already read the panel and had a chat with us about our research. The panel was fixed behind our table (Figure 11.5). Then, we asked if they had questions or doubts. We used this moment to explain to them what we had done in Vila Rosário, to make sure they really understood

FIGURE 11.5
Running the workshop and a part of its layout

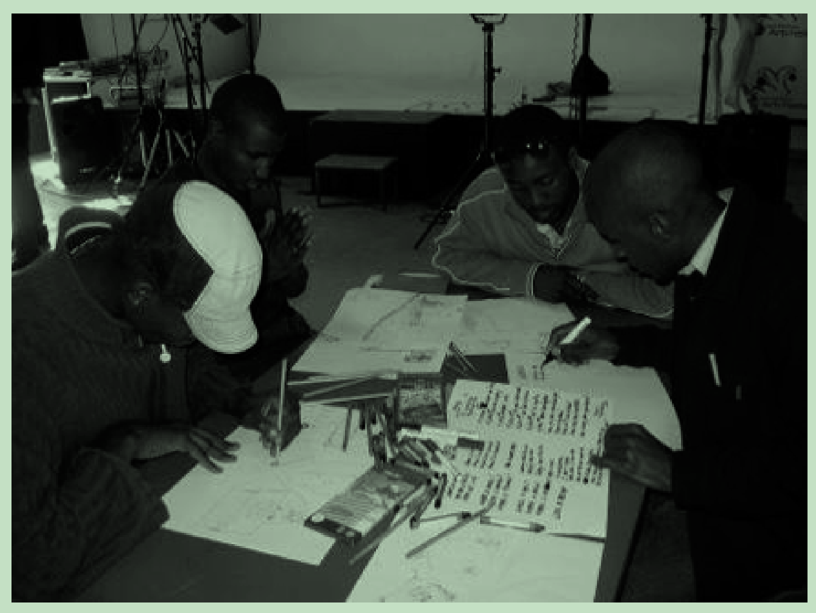
our concerns. It was important forus to know (and to hear this from them) that the majority of the participants came from a neighborhood like Vila Rosário, or had worked with similar communities. We also used this time to confirm some background data like the participants' age, profession, educational level, marital status, and experience with computers, mobile phones, and the Internet.

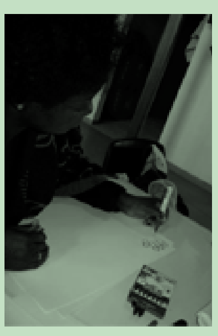
FIGURE 11.6–11.9
Drawing the symbols

Drawing icons

After about ten minutes of chatting, we asked the participants to draw an image that could be representative of some words on the website. To avoid any misunderstanding related to my English accent, we wrote down each word as well. We asked the participants to think aloud when we were doing the drawings. We tried this first to understand whether this kind of procedure could influence or distract others. To our surprise, however, the participants were so concentrated in their task that they did not pay attention to others. We saw only two participants trying to find inspiration in their colleague drawings and on-going thoughts.

We started this phase by following the production method explained above to avoid influencing the participants by giving them examples of icons from Vila Rosário. We were also afraid that we could affect their perception if we started to tell them how icons were going to be designed in the workshop. We chose to proceed by saying the word while not showing any clues to the participants. We asked them to draw an image or those images that came to their mind when I was saying the word. Material used in the test was A4 and A3 paper, color pens and pencils, crayons. Figures 11.6–11.9 show participants while they were drawing the symbols.





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As Formiga (2002) says, such a non-suggestive approach is important in understanding users' perception of the symbols and their functions. Formiga's production method proved to be a good way to approach the users' sensibilities and their ability to notice and understand things.

FIGURE 11.10
Symbols for home

The first symbol: Home – casa – house / lar - home. In Namibia we found a reality very similar to Vila Rosário. For the Namibian participants, the house is also a place to share important things with people who are important to you.

Some students, as well as some members of our group, had never had access to a computer. They had never surfed the Internet and they had never thought about using the house as a symbol for a place in which you find protection and love. Even though we had explained to them that we are developing a symbol to be used on the Web, the participants still tried to capture the real feelings people in the Namibia had about their house. Despite our explanations and information about the Project in the panel of our action station (Figure 11.5), reality proved to be stronger than our need for symbols.

Interestingly, a consultant on social issues projects focusing on rural development in Africa was participating in the workshop. She immediately understood the importance of appropriating the community's reality to reach an efficient design.

In Figure 11.10, there are some examples of the drawings. They represent the symbol Home. Two participants chose to write and not to draw. In their opinion, they could give us more content through words.

In drawing number 1 home is Namibia – the country – and inside the map it is possible to see the phrase: "In Namibia, people

1
NAMBIA
HOME is
MY FAMILY
2
Home:
3
4
5
6
Chickens
Main house
Toilet
water
veg. garden
7
8
HOME?
A HOME is MORE THAN A PLACE TO STAY:-
Home IS A PLACE OF:-
① SHELTER – roof over your head.
② FOOD – where you are sustained
③ Love – Family cares about each other.
④ Safe – Home is where you feel safe.
⑤ Home is where your heart is.
This is what Home should mean: BUT!
in MANY PLACES in THE WORLD WERE THEIR is POVERTY MOST PEOPLE | who live in poverty Do not have a Home.
A real Home should be a basic right to all people & children but in reality a home is a Luxury
9
Home
"Eumbo"
A place where we live,
A place where we are longing
A place where we feel Safe
A place where we feel Well-comed
A place where we feel at peace
A place where we live together
A place where we share together
Home is a place where we feel good
Where is my home?
Where do I feel at home?
Home exist only in our MIND
Home Country, where your heart is?

are always smiling!". Besides the map of Namibia, we can find a drawing of her house and her family.

In drawings 2-4, the participants had tried to draw different formats of houses. They told us that the most important thing is not the shape of the house or its material, but the privacy you can find in your home. You are the dweller. You can invite who you want to come inside to share that place with you. You have a place in which you can be with your family and have your own rules. Even if you do not have an active voice in your society, in your house you can be comfortable about your ideas. In drawing number three, we can perceive a man seated in the doorway of his house as if he were a guardian.

Drawing 5 shows another interesting aspect connected to community life. You may have your private space in your house, but you also have to bring food and drink outside to share with your neighbors. They may not have enough money to afford these foods or drinks, but more importantly, this drawing is about a moment of socializing and sharing. However, it happens outside the home.

In drawing 6, it is possible to see the main house, the bathroom outside the main building, well (or artesian well) when they don't have access to running water, a vegetable garden and chickens. Drawing 7 shows the costumes and values of a community. It has a fence, which divides two areas of land. Inside the community, there are houses of different shapes, which shows that even in the same community, people are different and cannot be seen as having the same values, skills, and so on. At the same time, the drawing shows that as designers we need to go beyond the fence to feel the environment and to understand and respect the differences between people. To reach our objectives, we need to have community member's

commitment and respect, and a part of that is recognizing and respecting differences in the community.

In drawing 8, the participant wrote down her experience as a consultant for sustainable projects in rural communities. She writes: "A real home should be a basic right to all people and children, but in reality a home is a luxury." Once more, we see the ideal clashing with the reality. In drawing 9, the participant wrote down the words that translated some emotions we could find in the other drawings. I have to highlight some interesting phrases that are connected with the discussion above:

> "Where is my home? Sometimes you can find this sentiment in people from marginalized communities. They can find more support in other places than their houses, and they feel themselves confused. Sometimes they go to other places to find comfort and safeness. They just escape from their reality. When do I feel at Home? It is interesting to think about it. Some persons showed us that at IVR they feel themselves at home. Home exists only on our MIND."

It is interesting to note that here, the participant said that the home exists only on our minds. He thought that people from vulnerable communities may live somewhere, but are feeling that they cannot afford a real home. He stressed this thought also when we discussed health, alcohol, education, running water, and so forth. Even before the workshop, he talked to us about the situation in vulnerable communities. He was talking about Namibia and asking about Vila Rosário to compare their situation.

Through the think aloud process, we could have a solid understanding about the concept and meanings of some key elements in the local community in Namibia. The workshop was more than just understanding the graphical elements: our objective was to understand the concepts behind the words. We wanted to understand local perception about some of the

key themes marginalized communities have to grabble with, and which are the most relevant points to be worked first, to reach a sustainable community. We learned that the meaning of home is not massively different in Namibia and Vila Rosário; the main differences are in the outward appearance.

FIGURE 11.11
Health Agents as a symbol

Symbol for Health Agents: locals or medical specialists. Figure 11.11 shows the drawings for a symbol for Health Agents. There were a few recurring themes in these drawings. First, the participants understood the Health Agent concept well, and stressed features similar to those Health Agents were doing in Vila Rosário. For example, in drawing 1, the nurse is giving advice about the importance of washing fruits before eating them, which illustrates how Health Agents can educate people about hygiene. This theme also appeared in drawing 8, which talks about the importance of having clean water, access to health care, and eating healthy fruits. Health Agents are persons who can teach people about these and other things. Drawing 11, on the other hand, is about the importance of training people from the community to act as Health Agents. Drawing 2 shows Health Agents as persons who make house calls without any regards to the patient's age, gender, or race. It also shows that Health Agents provide support for young mothers and babies. Drawing 10, in its part, says that Health Agents are people from the community, and always available to give support and help people. As the participant who drew this picture told us, the figure gets an almost religious meaning:

> *"Who is she? A nurse, doctor... I don't know. How should I call her. She better be called an Angel, busy caring and showing love, treating others with love. But she may feel helpless too, who helps her?"*

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FIGURE 11.12
Symbols for maps and search

Some features attributed to Health Agents were different from Vila Rosário, though. In drawing 3, symbols given to Health Agents were a red cross, a stethoscope, and a briefcase with the cross. These, of course, are easy to understand, but confuse doctors and Health Agents. Drawings 4–7 make a similar confusion in showing methods of transport that are much more hi-tech than in Vila Rosário. In Vila Rosário, Health Agents are people from the community and therefore are easily accessible most of the day seven days a week. They do not need ambulances and bikes for access. A similar association seems to be happening in drawing 9 that associates health care with monetary economy, which is not what Health Agents are about.

The drawing task shows that the concept of Health Agent may be difficult to communicate in a community in which the whole idea is new. If there is no practice underneath, the symbol gets too medical a meaning.

The map symbol: directions and zooming. Figure 11.12 collects together the drawings about maps. The figure gave us grounds for a few observations. The majority of participants drew a map like in drawing 6, showing landmarks like the most important places in town, or easy places to serve as a reference when getting lost. Another common idea was directionality. Maps were seen as "diagram[s] to direct a person to a desired destination," as drawing 4 says. Variations of this theme are, for example, in drawing 3, which is schematic and stylized, and in drawing 2, in which a map gives directions, as if it were a compass.

There were a couple more interesting design ideas as well. Drawing 5 presents the idea of zooming. The drawing is trying to show the importance of having a global view to have a better understanding of the place. So, here we see Namibia, Windhoek,

POTENTIALS

and did a kind of zoom in Studio 77. The map gives directions at all steps. Drawing 1 took a more global approach. In this drawing, there is a world map and plane routes that show connections between countries. This drawing was about the Internet and globalization. This was the first drawing with the Internet appeal we were after. Here, the "virtual world" seemed to come before the "real world," not vice versa. In this drawing, the participant thought first about our future plan of making the IVR web page a global democratic space to share knowledge. So he drew a world map and then thought about the Internet as a space to connect different places, cities, and societies.

Symbols for search: books and people. On drawing 1 in the lower section of Figure 11.12, one participant tried to think about the most common ways of "searching" in her life. The computer may be connected to the Internet, but she said clearly that in Namibia, access to the Internet is rare, and few people have a computer and an Internet access at home. Therefore, it is better to search better symbols for search. Her list consisted of traditional media: newspapers, magazines, and books in libraries. She also underlined the importance of having good libraries for research. The majority of the students cannot afford books, including students taking part in the workshop. Still, books are a good symbol for search: drawing number 3 used a book plus a magnifier lens to show where information can be found.

Drawing number 4 also presented a book as a good symbol for search, but the participant added that especially in rural areas people search information from other people. This idea was corroborated by drawing 2, following the same concept: inquire people to have/find information. Drawing 5, we got another message, stressing to us, as designers, that "*the local is the expert in their own area.*"

Symbols for contacts: human connections before technology. The upper part of Figure 11.13 compiles suggestions for "contacts." The diagram (drawing 1) tells about the importance of communication during human contact (see also drawing 4). It argues that when working with communities from rural areas, we need to understand the importance of an efficient and effective process of communication between humans. The communication can be done by sound, by conversation, by letter. And we need to consider that the people not necessarily need to be literate. So, we need to take care of what kind of language is more effective for that person, that community, that society. People need to understand the message, and we need to express our ideas respecting their local knowledge and work in their own language. Following this line, we could have built messages into a game, a picture. We can draw and can dramatize it, as long as we find symbols known to the local population.

Other suggestions that came from the drawings went beyond personal contacts. Drawing 2 took me back to my childhood. Drawn is a can telephone, a "toy" that we do not see any more in the so-called developed societies. However, it is very common in marginal communities, where the children still do their toys using scrap materials. Drawing 5 shows us that some communities, especially in rural areas, can only be accessed by things like an ox-cart. Drawing 6 shows a letter, which is the traditional way of contact, though it is disappearing in so-called develop societies. Drawing number 3 shows a public telephone: people often need it for example for contacting someone, or for booking an appointment at a hospital.

Finding symbols for FAQ: the question mark. The lower part of Figure 11.13 shows six drawings suggested for Frequently Asked Questions (FAQ). On the first diagram, the writer explains

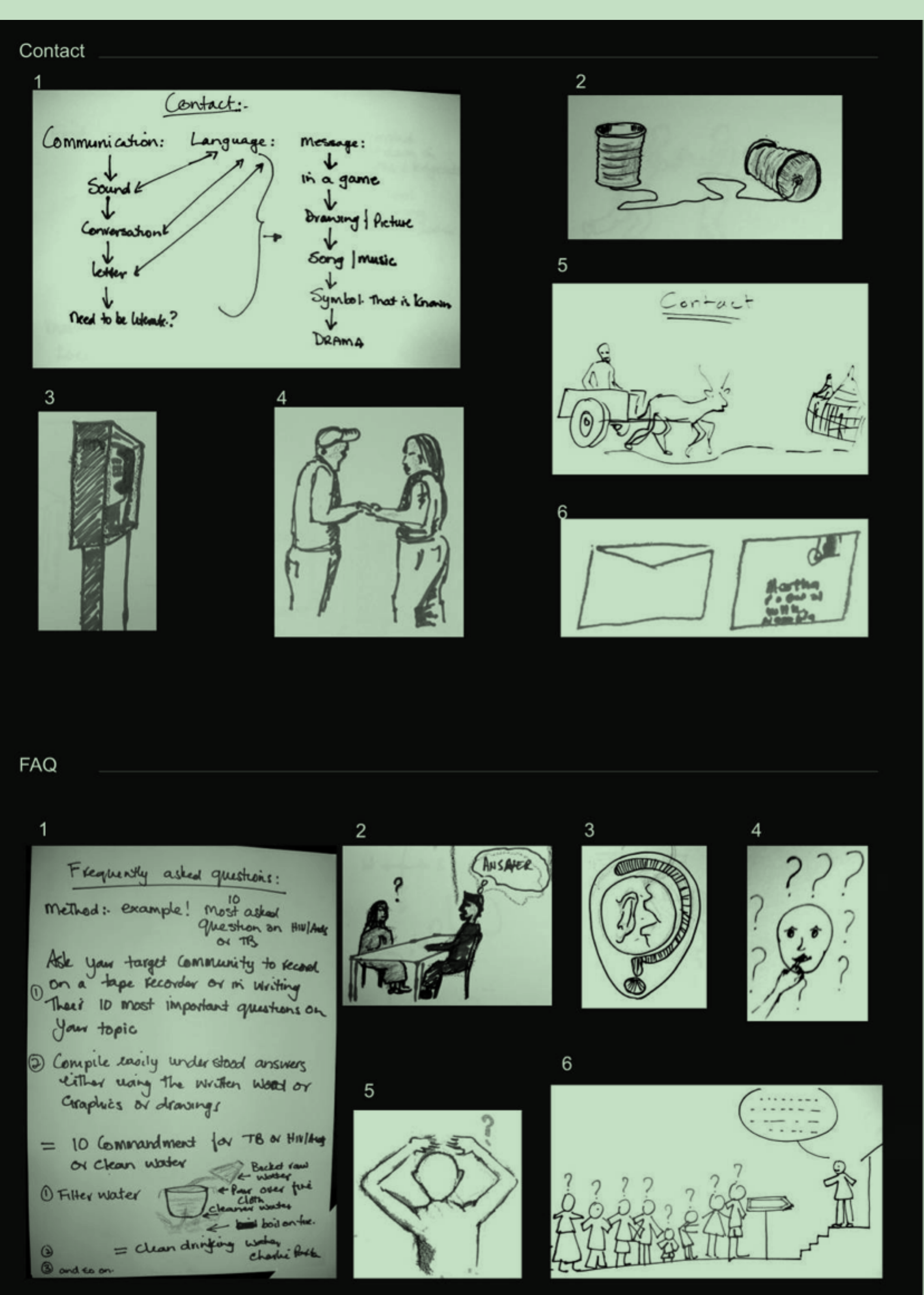

Contact
1
Contact:-
Communication:
Language:
Message:
Sound
Conversation
letter
Need to be literate?
in a game
Drawing / Picture
Song / music
Symbol. That is Known
DRAMA
2
5
Contact
3
4
6
FAQ
1
Frequently asked questions:
Method:- example! 10 Most asked question on HIV/Aids or TB
(1) Ask your target community to record on a tape recorder or in writing their 10 most important questions on your topic
(2) Compile easily understood answers either using the written word or graphics or drawings
= 10 Commandment for TB or HIV/Aids or clean water
(1) Filter water
Pour over fine cloth
cleaner water
boil on fire.
= clean drinking water
(2)
(3) and so on.
2
ANSWER
3
4
5
6

FIGURE 11.13
Symbols for contacts and FAQ

methods to reach people who need information about HIV/AIDS and about tuberculosis. She is working with communities from rural areas and she is always highlighting the need to apply efficient and effective methods of research, to reach an adequate process of communication with the community members.

Interestingly, practically all other drawings built about the question mark, showing how questions are asked in a variety of social situations. For example, drawings 2 and 6 illustrate a common way of asking questions. In drawing 2, we can see only one person asking a question; on the other hand drawing 6 shows a lot of people having questions. Drawings 3, 4 and 5, in contrast, use the question mark as symbol of question. Drawing 3 situates questioning to conversation, while drawings 4-5 show a confused individual.

Here we have a fairly clear result, suggesting to us that the best way to communicate FAQ must build around the question mark.

Reflection

The Production Method approach provides outcomes that allowed us to understand which graphical elements are meaningful enough to enter drawings. It was interesting to perceive that when the workshop was taking place, Marcelo and I started to see many clues about which things from reality participants will choose as significant symbols, and why that selection happened. When we were analyzing data, these cues became even clearer.

During the treatment of data we also could understand the similarities and the cultural differences between Vila Rosário and the Windhoek workshop. The material and feedbacks we received in this stage were analysed by us immediately after the workshop. We synthesized the results and presented them to

the participants on the next day of workshop. We took photos of all drawings and kept two diaries (I kept mine and Marcelo his), in which we took notes of the think aloud exercise for posterior analyses.

Our initial assumption that we had to redo the skin of the Instituto Vila Rosário website (and other designs) to make it work in Namibia was mostly correct. As the reality is different, so have to be the symbols that represent it.

TESTING THE WEBSITE: COMPREHENSION, HIERARCHY, AND SKIN

In the next stage of the workshop, we analyzed the Vila Rosário website with the participants. Following in Freire's spirit, we wanted to make the process as dialogical as possible; just using the Brazilian symbols would have been an oppressive move. Here, we gave the symbols developed in Vila Rosário to participants in Namibia to elicit their opinion about them. We applied the Comprehensibility Judgment Test as a start, to reduce the number of variants that we will use in the workshop. The Comprehensibility Judgment Test is a paper-pencil test that is conducted in order to determine which variants are considered better comprehensible than others (Zawaga 1989, Brugger 1999, Formiga 2002).

First the participants received the symbols we drew with people in Vila Rosário. The participants were asked to separate them into categories according to what they referred to (Figure 11.14). Then we asked them to explain their choices. We decided to work with the group as a whole. We wanted to have the group's feedback about the graphical elements, as we saw the discussion with the groups as more valuable for us than individual opinions. We already knew a lot about their individual thoughts after the previous phase of the workshop.

FIGURE 11.14
Sorting symbols into categories

FIGURE 11.15
Using the whiteboard

We wanted to understand the participants' ability to identify the meaning of the symbols. Another thing we wanted to know was whether there are conflicts between different perceptions. These questions helped us to have a deeper understanding about the symbols and whether they were comprehensible. As we have seen, some of these choices were not obvious. For example, it was clear that it was difficult to find symbols for functional referents like "search."

In this test, we gave a magnetic board and the symbols printed on a magnetic paper to the participants (see Figures 11.14–11.15). We wrote all the symbols on post-its and asked people to match them with referents. We did not interfere during the matching process. We recorded the discussion and took notes on our diaries, and we took some photos of the process and the results.

After the participants had matched the symbols with referents, we asked them to arrange the symbols by level of comprehension and to choose a color that could function as the background for the symbol on the web page. We asked them to arrange the symbols and the colors from the easiest to

understand to the most difficult to understand. Figures 11.16–11.18 provide snapshots from the process.

Next we asked the participants to sketch a web page. Participants were free to use the symbols we gave them, but they could also draw new ones. We told them how to proceed, but they had to justify their "design process" from the first thoughts to the results. For example, they had to explain these issues:

- Why they were using the symbols we gave them, or why they decided to redraw them;
- Their choices in terms of the context (and what was the context: real or virtual, local or global);
- Why the participants thought the symbols would work with people in other places and cultures;
- What kinds of color patterns they chose and why they chose them; we also asked them to explain why they thought those patterns would help their audience to surf the web page?
- Why is it important to understand the process to build a visual repertory based on local realities?

FIGURES 11.16–11.18
Arranging symbols and colors

In this test we allowed participants to choose one drawing from their own group. It was not mandatory to use our icons. They just needed to justify why they chose another draw.

The results of the study are in Figures 11.19–11.20.

It was interesting to see that the majority of women chose the eye as a symbol to represent search. In explaining their choice, they told that we need our eyes to see what we want, and we can find something if we just keep our eyes open. On the other hand, a large number of men chose the magnifier glass or the binocular as the best symbol to represent "search". In their opinion we need to have an artefact to help us to really see what we want to find.

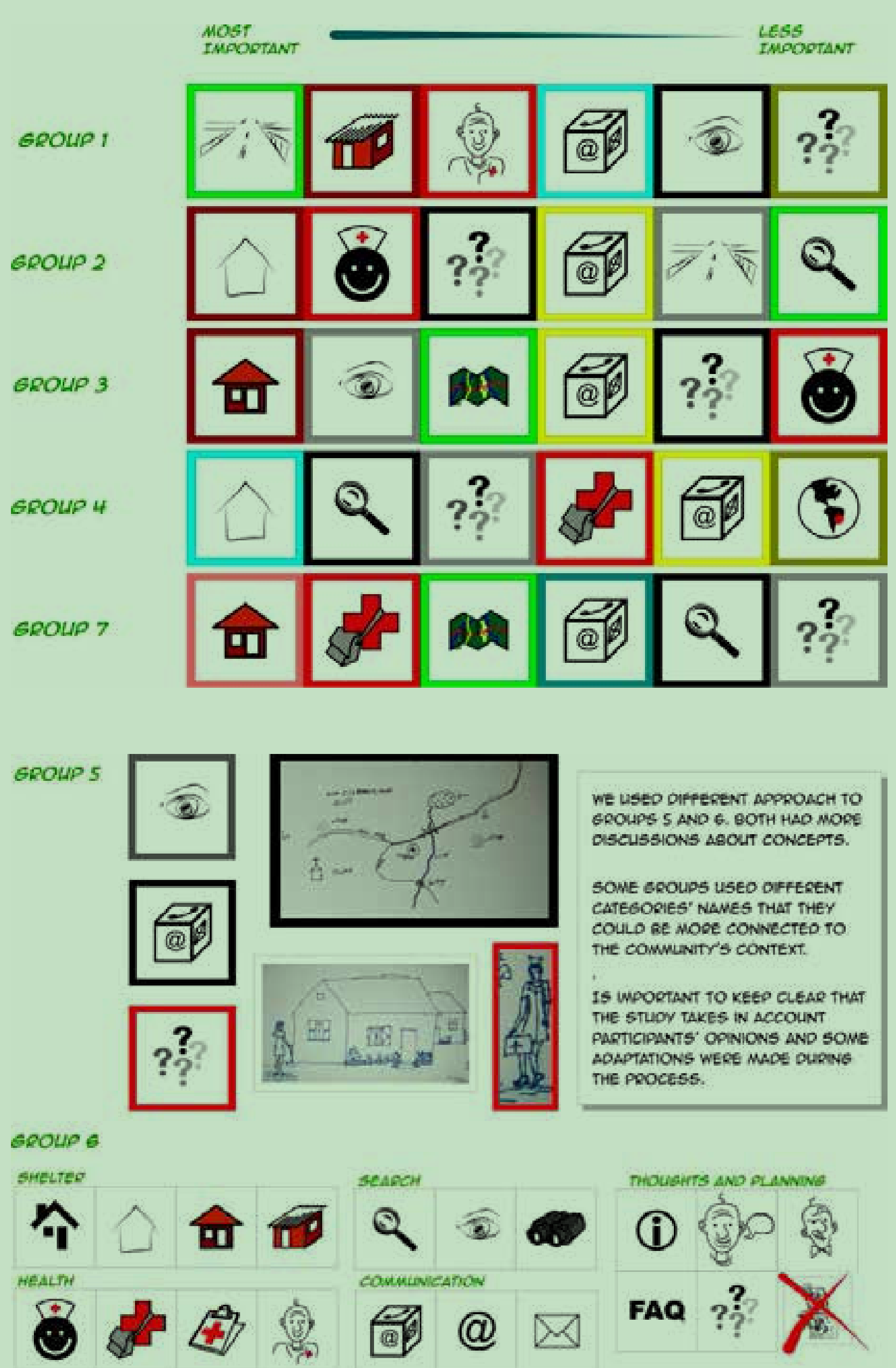
To Group 1, the symbol that we drew for information (the circle with an "I" inside) becomes an exclamation mark. The group categorized the symbol as information just like the others, but for this group, the meaning was "Yes, I can get the information I need from there." For them, the question mark also showed the feeling of having information.

Group 5 developed an interesting opinion about the most representative symbol for "information" in airports or in touristic points. They told that when we are travelling, we want to know information about our locale. We want to know where to go; we do not want to be lost. So, the best symbol for information is a map, which we found surprising.

In relation to colors, the majority chose yellow as a background color because of the yellow pages. For the map they chose green because of vegetation in the landscape. For search, they chose gray, black or silver. In their opinion the technology was frequently connected to these colors. To FAQ, they followed the same color. One group said that they chose grey because grey is the "between" color of black and white. Also, they did not know if they were going to find the answer to their question. To

FIGURE 11.19
Symbols ranked in terms of their importance, decomposed by test groups

FIGURE 11.20
Symbols for the website for two groups



house, the majority chose brown because it is the most typical color of buildings in Namibia. Just one group chose white because the houses frequently are white inside.

Feedback from Namibia to Vila Rosário

As I have said earlier in this chapter, the long-term goal of the Instituto Vila Rosário project reached beyond the state of Rio de Janeiro. The long-term goal of the project was to have a transnational democratic online space for sharing experiences and knowledge about how to treat communities. For this purpose, we need to take into account the backgrounds of diverse audiences (doctors from Brazil who work with communities like Vila Rosário, doctors from Brazil who work in private hospitals, doctors from abroad, local communities, etc.). The Namibia workshop was for us an opportunity to get a hold of some of these issues by testing our design process and our designs.

All the results we had in Namibia, especially those results different from the results we had in Vila Rosário, were sent to Vila Rosário and tested again. The main group of Vila Rosário's web page users will be Health Agents and specialists from the Vila Rosário Institute. Because of this, the tests were done with them.

This was to become a model for the project as a whole. Whenever the Vila Rosário model was applied elsewhere, it had to be given local flavor by changing its symbols, categories and possibly, contents. Then, as these were settled, there was to be a feedback loop to Vila Rosário to keep the process open and democratic.

12

Conclusions: Years After

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Coda: Ambulatório
da Providência

The initial idea of this research seemed initially pretty simple: it was to develop a web page for an invisible community in Rio de Janeiro, the city in which I was raised. Very simple it seemed, at first. I was in Finland doing my doctoral studies, and I had all the technologies I needed to stay close to the community, and needed to understand their needs.

This scenario changed as soon as we started our research, however: we were doing a research with and for a community that lives in a very different world from ours. They are stigmatized; most of them do not feel to be a part of the "mainstream" society. They do not trust outsiders before they know the outsider is trustful – from their point of view. Methodologically,

the interesting point is that sometimes you as a researcher feel that they trust you, but in reality they are still suspicious of your real motivations. Facing this situation, I was afraid they would tell you what you as a researcher want to hear from them, rather than tell about their reality.

Our starting points were empathic design and early participatory design (see esp. Koskinen et al. 2003; Mattelmäki 2006; Mattelmäki et al. 2014; for participatory design, our main reference was Ehn 1988a). These frameworks told us to get an insight into the local form of life, as Marcelo Judice says in his dissertation, building on the late work of Ludwig Wittgenstein (M. Judice 2014). They came, however, from advanced and very equal Nordic societies. We felt that they would not work well in Vila Rosário, or any other place like it. Simply, social distance between us and people was massive; it was not just the distance between a university-based researcher and a professional, or people with a white-collar background and people who were blue-collars. A *carioca* by birth, I could not take for granted much background knowledge of the culture I had to empathise with.

Here, Paulo Freire came to the rescue (Freire 2005). As a fellow Brazilian who had done the same journey, his advice gave us confidence about our chances of making contact with the locals. He also gave us an initial process of interpretation, and a suitable translation between social science ideals and the Brazilian realities. As Freire tells, when a researcher goes to the field, he needs to understand that the answers to his questions do not come often from the words, but they may lie in the gestures, in silence, in the "I do not know". From Freire, we learned that to have a deeper understanding of the context you need to "impregnate" yourself in the day-by-day doings of the community, in every sense of the term.

CONCLUSIONS

Building on his experience, we built an approach for working with designers in the community. Our methodology became much more complex than a typical Web design process that consists of a short contextual study (for example, Beyer and Holtzblatt 1998), paper prototyping with a cognitive walkthrough and, after the actual design phase, usability tests. In contrast, our methodology took us to Vila Rosário; it brought us into a long-term contact with Health Agents and doctors; built on local institution, Instituto Vila Rosário; and led to an iterative cycle in which we constantly built and tested designs, while doing most of them together with other people. Throughout, we used many methods typical to contemporary design research, including cultural and empathy probes (Gaver et al. 1999; The Presence Project 2001; Mattelmäki and Battarbee 2002), magic things (Iacucci et al. 2000), interaction analysis (Jordan and Henderson 1995), and many others.

Beyond all these methods, however, were our process and the Freirean vision of a dialogue of equals. We also believe that although our approach built on a background different from Brazilian social design (see esp. Couto and Ribeiro 2002), our studies are well in line with its spirit, and do contribute some things to it: some literature, an approach, a useful process, and many methods.

OUR DESIGNS

Our work became visible in our designs. Through the experience we shared with the community, the most important point was to help the Health Agents to develop better services for the community. During our research process we could observe transformation in their practice, and we are still observing it.

For us, the integration of an ethnographic approach to empathic design was fundamental in understanding Vila

Rosário and its real demands. The interdisciplinary and the transdisciplinary aspects of the process were important as well, although they stayed in the background, much as in Freire's *The Pedagogy of the Oppressed* (Freire 2005). A project like ours stimulated practical and realistic interaction between researchers, community members, the IVR team, doctors, nutritionists, and so forth, all with different backgrounds. It also brought scientific and medical foundations (FAP) and academic bodies (UFRJ, PUC-Rio, UnB, Aalto University) to the same table. Essential to this cooperation were the designs and the way in which they were made. They were "design things" in the sense put forth by Binder et al. (2011). As Binder and his colleagues note, the word "thing" in English comes from old Scandinavian "ting," which means a parliament, an agora, a place where people gather to talk about their concerns. As design things, probes, mock-ups and prototypes provide a place for people to gather and talk about design; this is what we saw all through our study. The focus of people we worked with was not on us, but on things we created. They greatly appreciated the effort we put into our methods and designs; this became the basis of trust in our work.

In this kind of process, is it not possible to do your design and release them into the context. We needed to find the key persons and we had to help them understand what we were doing and why our designs were what they were; we needed to help them understand our design thinking and how we worked with it in their thematic universe (as Freire might have put it).

The holist approach to understanding the chain of poverty was essential to us, and we shared this understanding with Drs. Costa Neto and Castello Branco, who were the key gatekeepers of the Institute. A project like the IVR in its own way already builds on Freire's pedagogy of the oppressed, in that it was a part of the community and its form of life. We shared the aim of

the institute: our joint aim was autonomy, making people stand on their own legs. Another lesson learned in this context, which also corroborates Freire's thoughts, is that the condition of solidarity is a human necessity in surviving the hardships of life in a poor urban neighborhood like Vila Rosário.

TEACH A VULNERABLE MAN TO FISH

Our ideal in Vila Rosário was to help the community to find its own ways to develop. During the research process, it was clear to us that they needed to feel themselves comfortable and confident about their strengths. In their opinion, a researcher cannot go to the community for a short while, develop a project, and leave without seeing the real impact of his/her project in the community. The true measure of a project like ours was how it became interwoven in community life.

So, we learned from them that in some situations, we first need to give them the fish , so they will be strong enough to start to believe in their selves, but the main aim is to learn how to fish. After giving them the fish, we needed to show them how and where the good fishing spots were, and only then teach them to fish. And in doing so, as a researcher, we had to keep in mind what kinds of tools they needed for fishing and for cooking the fish. This was empowerment: helping the community to help itself.

After having this though, I was talking to one Health Agent, who told me that I needed one more step: I needed to stay in touch with the vulnerable man to check if he would keep fishing years later. The measure of success must be whether he feels comfortable enough to go fishing by himself after the researcher leaves. If research goes back to his "old life" as soon as the researcher leaves, the study has failed in its aims. If that is the

case, the man needs more support to be really confident and not to give up fishing.

We did our design study in 2005-2008 mostly. Is there any evidence to show that Health Agents are still benefiting from our work?

One of the Health Agents, Clara, told us that for her one special thing about our design approach was that we are still working with them at the end of 2013. We are there to see and to analyse the impact of our designs. We are there to help them if they have doubts about doing designs by themselves. For example, we trained them to develop the journal by themselves (see the last section of Chapter 9). Now when they want to design a new number, they do their most. When the journal is almost done, they may still have doubts about something. If this is the case, they send a message to us on social media asking for help. Then we finishing it together, and in doing the journal, they are learning about how to do the journal without us. The most important point for them is that we are there to help them if they need. We know Health Agents personally; we worked with them; they learned from us; we learned with them. We want to see the impact of our designs in the community development, but this takes time, we have learned.

Right now, we are living in Brasilia. We are geographically separated by 690 miles (approximately), but it does not stop Health Agents from keeping us informed about IVR. Social media has come to help, as Figures 12.1–12.2 show, and we are still developing products together. This is a great result for us because it helps us to better understand what happens to our designs after they are off our control.

As I noted at the end of Chapter 2, our process went beyond our influences in one important matter. We have kept in touch with the Health Agents for years after our fieldwork. This has

FIGURES 12.1–12.2.
Health Agents are still in contact with us through Facebook

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 a lot more fluent users of these communication technologies, and have Facebook pages. It has been amazing to see the change from computer illiteracy to Facebook fluency.

Importantly, this has deepened our relationship with them a lot. 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. Going deeper in the context, using participatory and empathic design methods as a base to our approach we went on to apprentices, who want to learn about Vila Rosário – we experienced their own community with them, we sensed our own – and, over a few years we became friends.

CODA:
AMBULATÓRIO DA PROVIDÊNCIA

After testing our approach in Namibia and redoing our designs in Vila Rosário, we were invited to do another study to evaluate whether our research approach was transferable to Ambulatório da Providência, which is located in Vila Mimosa in central Rio de Janeiro. It is a clinic inaugurated on the 1st of December 1989. It had a history then. A group of doctors had started to work with local population back in 1982. The community of "Old Vila Mimosa" was (and still is) Rio de Janeiro's main red light district, and although its community was certainly visible, it was also stigmatized and vulnerable.

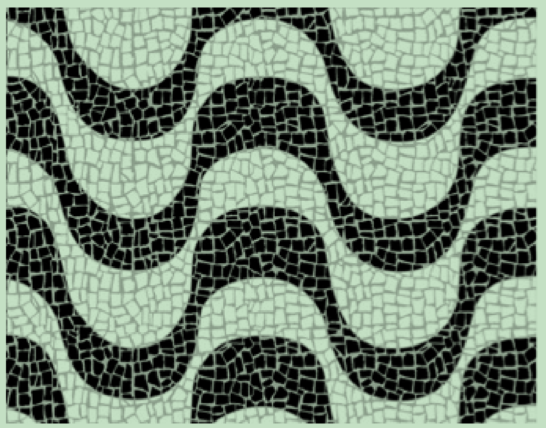
When the doctors started their work, about 70% of the women had at least one sexually transmitted disease (STD). After 25 years, the Ambulatory mostly focuses on people who are HIV positive. This population mostly consists of drug addicts; sex workers; homeless; ex-cons; and street children. Working with these patients, they often diagnose "opportunistic" diseases such as tuberculosis, syphilis, toxoplasmosis, and pneumonia. The ambulatory is located in São Cristovão, close to the place where Vila Mimosa was relocated by the city.

In 2010, we were invited to do a design project in Vila Mimosa by Dr. Luiz Roberto and Dr Maria Inez, the two stakeholders from the Ambulatory. They had known and followed our research in Vila Rosário. From their point of view, our design approach turned out to be very different from other design projects they had seen, for better. For Vila Mimosa, they also wanted a holistic approach, based on our knowledge built during our research in Vila Rosário. The empathic and participatory roots of our approach, as well as Freire's approach aiming at liberation were again necessary in understanding this context, which in

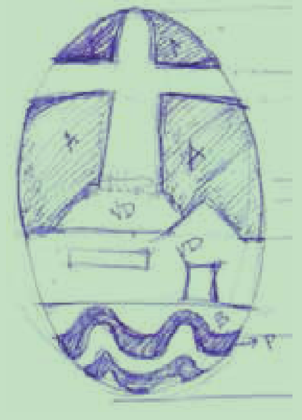
Ambulatory façade

The cross that is on the wall
Ambulatory since 1989

One of the main well-known symbols
of Rio de Janeiro: Christ the Redeemer



Another important symbol of
Rio de Janeiro: the pattern on
Copacabana beach sidewalk



Final sketch

The Ambulatory logo

FIGURE 12.3–12.8
How the logo was built. Starting from the main symbols connected to the Ambulatory team, to Rio de Janeiro city.

some ways was similar to Vila Rosário, but still quite different. The doctors wanted a design built on local needs, done in their context, and involving different people who are part of the day-by-day life of the clinic.

It was Dr. Luiz Roberto in particular, who kept reminding us that we should take advantage of our research and develop an approach that could be applied to different vulnerable communities – not only locally but also globally. From his perspective, we had to build a design approach that could be adaptable to any new context, but which had its base built on empathic design and ethnography. To him, such approach would help people fulfil their potential and find design solutions that can help them in their pursuit of happiness.

Thus, in the Ambulatory and in Vila Mimosa, we followed the same research approach we had developed in Vila Rosário and later streamlined in Windhoek. We developed a logo with all the members and stakeholders of the Ambulatory and it was successful (Figures 12.3–12.8). On the anniversary party of the Ambulatory an employee made a cake with the logo we developed, she said it was a tribute to the result obtained (Figure 12.9). We also developed characters, posters, signaling, games, webpage, and so on, again building on characters familiar in the community. For example, our characters for doctors built on Drs Luiz Roberto and Maria Inez (Figures 12.10–12.11).[28] Some uses of the logo are in Figures 12.12–12.13).

While the design process had taken almost two years in Vila Rosário, in Vila

28
We exercised some artistic licence here. When he saw his character, Dr. Luiz Roberto cried: "I'm not fat!" He is correct, no doubt about that. The chubby figure was more jovial, we figured, which justifies our artistic tease.

FIGURE 12.9
The celebration of the 20th anniversary of the Ambulatory. Dr. Inez receiving her friend, nowadays a Brazilian Cardinal.

Mimosa, the process was done in about two months. For us, this suggests that the process was "scalable," as Dr. Luiz Roberto had wanted.

In 2013-2014, the Ambulatory will change its location. The idea of Dr. Luiz Roberto and Dr. Inez is to renew our research in the Ambulatory and to develop new designs to their project. The project in the Ambulatory has helped us to streamline our approach further, but it has also helped us to better understand the value of our design approach. The new opportunity makes it possible for us to go deeper in some issues and to correct our mistakes in 2010. At a deeper level, it will help us to evaluate the transferability of our approach even in complex and dynamic communities like Vila Mimosa.

The question of transferability is relevant, of course. While the Windhoek workshops provided us a way to streamline our process from a year-long PhD study to something that could be done in weeks, Vila Mimosa was a way for us to think about how to apply our process and the results to places other than Vila Rosário. What we did in Vila Mimosa has affinities in community design. Terminology varies, but community-centered designers, who usually measure their success in terms of how well their design functions in a particular community, invariably face this question. Usually this issue is discussed in terms of replication or transferability rather than statistically. More recently, the issue is also handled in terms of incubators and business models as

FIGURES 12.10–12.11
Dr. Luiz Roberto and Dr. Inez, inspiration for the characters, and characters made by Nestablo Ramos Neto

FIGURES 12.12–12.14
Some detail designs: background screen, report cover, and logos showing how to and how not to get infected by HIV. Drawings by Nestablo Ramos Neto.

CONCLUSIONS

possible alternatives to the generalization problem, which we find as a particularly interesting analogy to what we did. Briefly, for us the way to generalize is to see the process applied in another community, but also to identify the key stakeholders who would keep the designs working even after we have left the scene (see Manzini and Rizzo 2011). What Marcelo and I added to this discussion is the long-term perspective, the need to keep in touch for years after through social media.

For us, the important thing is not, however, the academic argument about whether our process can be applied elsewhere, but who would do it. One very interesting thing to me was the spirit of our project. The Community Health Agents in Vila Rosário took the project to their heart. Today, they want to act as multipliers in other communities by sharing their experiences about the work they do, a tiny part of which was our study. They want to learn from others, and they want to become teachers who can share what they have learned. I believe Paulo Freire would have approved what he saw in Vila Rosário, giving his blessing to the Health Agents and to us.

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Andrea Judice (b. 1967, Brazil) did her studies of Industrial Design at Pontifícia Universidade Católica – PUC-Rio/Brazil. She earned her Masters of Psychology (focused on ergonomics) at the University of Brasilia – UnB/Brasil. Her research interest lies in User Centred Design, Participatory Design and Empathic Design. Her focus of attention is the application and the implications of these methods in social design projects for and with slums in Brazil. Her studies focus on information systems and aim to create design programs for vulnerable communities with little access to technology.

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This book describes design research related to improving public health in a vulnerable community in Rio de Janeiro, Brazil. The research has been done with Instituto Vila Rosário (IVR) that does long-term health work in the community of Vila Rosário. Specifically, it aims at empowering the Community Health Agents working for IVR.

The author studied Vila Rosário in depth to learn how people in the community understand diseases like tuberculosis and their causes. The study developed design products to improve the Health Agents' work. Throughout, the study built on participatory and empathic design, but went to their roots in Paulo Freire's pedagogy and Brazilian social design.

Fundamental to the research process were the commitment to the context and to its key persons. This book describes many of the lessons on how to build trust in this lovely, complex yet instigative community.

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