# Participatory Tensions in Working with a Vulnerable Population

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# ABSTRACT

This note uncovers a design tension in participatory design practice in the context of two organizations in Nepal working on reducing sex-trafficking and helping survivors. The dilemma consists of contradictions between the public face that the organizations present to the world and the more complex underlying picture painted by survivors. In initial work, we created and deployed a value-elicitation game for survivors that gave us better access to their voices. However, the implications for ongoing participatory work remain to be unpacked. The veneer may constitute a necessary part of the staffs' successful interactions with external funders. The survivors rely on the resources that the organization gathers, yet the veneer may also obscure some aspects of the survivors' needs. The question raised is "how should our PD practice position itself with respect to the ideal of comprehensive democratic participation when potential harm may ensue to vulnerable people?"

# **CCS CONCEPTS**

• Human-centered computing → Field studies; PD; User studies;

#### **KEYWORDS**

local partners, design games, goal balancing, vulnerable population

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#### **1** INTRODUCTION

In its 2015 constitution, Nepal for the first time asserted the basic rights of women. However, in practice, women still face barriers to owning property and have very limited recourse in the face of widespread violence. Nepal is a poor country with a major source of income from remittance from Nepalese working abroad (31.3% of annual GDP). Financial vulnerability along with limitation in other resources creates a space for tragic problems like female sex trafficking to exist and thrive (see for instance [18, 27]). Indeed,

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although accurate counts are difficult, the open border between Nepal and India is one of the busiest human trafficking sites in the world with between 5,000 and 12,000 girls trafficked annually. In addition, there is sex-trafficking within Nepal and a considerable problem of violence against women [27].

This note focuses on a design tension raised by the initial investigations, an investigation of two non-governmental organizations (NGOs) dedicated to reducing sex trafficking and helping survivors. These NGOs run shelter homes and livelihood-generating training programs for survivors [21], with focus on crafts. We set out to collaborate with these organizations to get an insider perspective and familiarize ourselves with the local dynamics [15, 28]. As we strove to understand the organizations, we became aware of some of the pressures and conditions under which they work. The NGOs present their work and their success through a focus on quantitative measures that simplify and arguably distort a more complex picture. To scratch the surface of this veneer, we designed and utilized a ludic participatory experience for sister-survivors (the formerly sex-trafficked women served by and reliant on the organizations). We encountered a classic wicked problem [22] in which possible PD approaches going forward vary depending upon how we formulate the important conditions and values.

#### 2 BACKGROUND AND LITERATURE REVIEW

The problem in the current paper can be conceptualized through the lenses of (1) participatory design (PD) practices and values and (2) the design tensions framework [26]. PD enables the engagement of people in more democratic processes under a wide variety of conditions and circumstances. It can be brought in at a number of different points in the design process [5, 6] and engages with the distribution of power in different ways (e.g. [9]). But it can be problematic to decide whose voices to prioritize, especially when considerable power differences are involved. Bidwell and Winschiers have separately made sophisticated arguments about work with first peoples in Africa and Australia [2, 28], arguing for sensitivity towards existing relations and power structures, including deference towards elders. But it remains complex to know what to do when organizations are multi-layered. Brereton and Burr [7] address the issue of promoting PD when some stakeholders have different interests in the project than those that engage in the PD process. Not everyone has to be involved the same way. Kyng has also argued that while "proper structures for participants and their 'group interests' are important ... developing these structures need not be part of the results of PD, at least not explicitly consciously-executed PD" [20, p. 15].

The design tensions framework points out some of the challenges that may be associated with research work in this context by conceptualizing design not as problem-solving but as goal balancing [26], where the goals to be balanced, even the participatory goals,

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maybe incommensurate. Design tensions draw explicit attention to the need for elaborated and articulated reflection on potential design action when conflicts are inherent and conditions for explicit joint discussion with all stakeholders may not be obtainable or even desirable. Our initial impetus was to focus on the sister-survivors; however, to gain access we needed the organizations and these turned out to be an on-going context.

# **3 METHODOLOGY**

This study integrates initial ethnographic work with a value-eliciting activity for the sister-survivors. The value-elicitation activity was a component of the PD. Additionally, the intention was and is to arrive at a PD approach to future interventions. The ethnographic study was begun to get a holistic view of the NGOs' operations and understand the staff members' perspectives. After several months of email correspondence, phone, and Skype calls, during four weeks, the first author visited offices of two organizations, interviewed 10 staff members, observed three key players at work through shadowing, conducted supervised group discussions with nine sex-trafficking survivors living in rehabilitation homes, and finally engaged in the value-eliciting activity with five survivors at one home. All sister-survivors were females between the ages of 18 and 23. Staff members ranged from the founder of the organization, the director, the program officer, and the rehabilitation-home warden. All work was conducted in Nepali, the primary language of the interviewees and first language of the ethnographer. Interviews and group discussions were audio-recorded, transcribed, and partially translated into English. Field notes were taken throughout.

# 3.1 The Local Partners

Both organizations shared the aims of preventing and rescuing sextrafficked women. Both provided rehabilitation homes with training in crafts and support for independent living. Both organizations have existed for more than 15 years, and employ more than 100 staff members. In one, staff members "at program officer levels or above" (P3) were professionals who generally had formal education at the master's level in business or social sciences. Henceforth, we call this organization Professional Organization (PO). Importantly, the staff at the highest level of the other organization included many people who are themselves sex-trafficking survivors. We call this organization Survivor Organization (SO). Although most sextrafficking survivors are semi-literate [27], many but not all leading SO have gone on to obtain college and even master's degrees.

As is typical, 60.7% of SO's annual funds in 2016 were from donors. As with other NGOs, donation and aid are conditional upon quantitative measurement (see for example [11, 12, 23]). Under these circumstances, other studies have found that plans and priorities could be driven by donor's interests and values [8] and regulations enforced by the government [17].

# 3.2 The Sister-Survivors

Estimates of the number of sister-survivors rescued each year in Nepal range from 2,000-3,000. PO housed 250+ survivors in its shelters during the 6-month cycle that included the investigation reported here. SO housed only 32. Both organizations also help non-resident sister-survivors, especially with legal support. Sister-survivors come to these centers through various mechanisms. About half of the women in SO had been located by an NGO in India that worked with SO on repatriation. PO also reached out directly to sex workers in and around Kathmandu and attempted to stop possible traffickers at the Nepal-India border.

#### 4 INITIAL ETHNOGRAPHIC FINDINGS

Three elements of interaction with the staff stood out: forms of address, focus on quantitative measures, and criteria for success.

#### 4.1 Forms of Address

On the websites, "victims" and "survivors" were both used to describe the women who were being or had been served by the organizations. Face-to-face, PO staff called these women "clients", "service-receivers" and "beneficiaries". In contrast, the staff at SO used words that translate to "younger sister" or "older sister", which are honorific and more familial terms. This variation in forms of address seemed to reflect different orientations towards the survivors.

Following Spradley's suggestions [25], here we use the term "sisters-survivors" to denote these women and differentiate them from the survivors who worked at SO. We note that sister-survivors referred to staff members as "mommy", "older sister" or (for men, including the ethnographer) "sir".

#### 4.2 Focus on Quantitative Measures

One of the most striking things about our initial encounters was the extensive use of and reference to quantitative measures in both organizations. Number-laden posters adorned the buildings. Some of these implied numbers unlikely to be true in a meaningful way. In one case, the number of women reported as rescued/intercepted consisted not of sex-trafficking rescues but of the total number of cars checked and "suspicious looking" people interviewed at the border. Other numbers included people who just happened to be nearby when mass awareness announcements were made. Other critics have questioned the numbers and the lack of evidence of effectiveness (e.g. [19]). However, the use of quantitative measures is canonical in NGOs of this sort [12, 23].

One question became how the focus on numbers affected the sister-survivors in processes of reintegration. There was a distinct difference between the organizations that paralleled the difference in terms of address. PO displayed *only* numeric posters. SO *also* showed posters made by the sister-survivors. Correspondingly, rehabilitation was defined at PO as a process to be undertaken, of going through 5-7 months of living in the rehabilitation homes participating in training and 1-2 sessions of counseling, followed by 6 months of tracking. SO's process was described in terms that seemed somewhat more responsive to the individual needs of their smaller group; sister-survivors could stay as long as they needed.

#### 4.3 Criteria for Success

Consistent with the focus on a relatively impersonal notion of quantitative effectiveness, PO staff members used the language of opening and closing files to describe handling particular cases. One staff member talked about their criteria for successful integration of sister-survivors into society, commenting that "If we do not encounter any problem in six months, we *close their files*". Participatory Tensions in Working with a Vulnerable Population

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"Standing on one's own feet" was a phrase frequently used by both organizations to describe success. When asked to define it, five staff members offered that the sister-survivors would find a job or start a business. Indeed, each of nine success stories shared with the ethnographer involved sister-survivors starting a business and therefore (in PO) allowing the organization to *close files*.

### 4.4 Hints of a More Complex Story

Two kinds of hints of more complex stories emerged during initial ethnographic work. Like Alcoff [1], we encountered staff members speaking *of* and speaking *for* the sisters. More particularly, staff members would gently correct the sister-survivors, asserting, for example, that independence was their goal. We also uncovered complexity in one of the success cases reported by PO. With financial support from PO, four sister-survivors had opened a sewing and tailoring shop. After six months with "no problems", PO closed their files. Visiting that shop, a year and a half later, we found it run by a woman who was not a sister-survivor but had been allowed to take over the venue after it had been closed. It could be argued that the four sisters had been reintegrated to society; however, if true, the story raises questions about longer-term prospects for sister-survivors.

# **5 LISTENING TO THE SISTER-SURVIVORS**

We used a method based on photographs with sister-survivors aimed at eliciting their voices and values. Our hope was to draw out multiple, personal interpretations which could lead to a deeper understanding of the context, corresponding to Sengers and Gaver's highest level of interpretation of probes in which users reflect on their personal and cultural values [24]. An initial thought was to ask them to recount their life stories. However, in group interviews, sister-survivors reported pain associated with doing this previously; one sister-survivor said, "It was hard.... while I was writing the story, having remembered incidents from the past, it hurt. I even cried. I cried not understanding why we had to revisit those old events that we had long since forgotten. At one point, I even told them that I won't write it."

Given this, we focused on their current and future lives. We utilized a ludic experience collecting and discussing photographic artifacts [3, 4, 10, 13, 14]. The primary goal was to elicit the women's own words in a positive context, accommodating their semi-literacy and using materials and methods that they would experience as fun. Like similar probe activities, we gave the sister-survivors a camera to create their own pictures for two days. The widespread presence of handmade posters throughout the SO buildings, consisting of cutting from papers and magazines pasted onto large sheets of paper, suggested that a similar kind of activity would be comfortable.

Two days prior to the design game session, we met with five sisters living in a shelter home. Only one had prior experience using a camera. None owned cell phones. However, all had seen someone else use Facebook to display pictures. During the session, we showed them how to use a Polaroid-style instant camera. We left the camera with the sister-survivors with the request that they take any pictures they wanted to, respecting possible danger associated with showing faces. Our adaptation of the photo-elicitation method involved handing each picture around a circle for discussion by

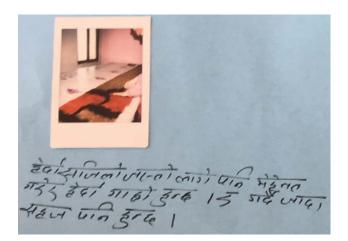


Figure 1: A sister-survivor working on a traditional woolen shawl. The text reads, "Although it looks easy, it [shawl] requires hard work. With effort, it gets easier over time"

each participant. At the end of each round, participants put the photo on a poster with a short negotiated statement. The collective production of the statement created a product that was implicitly personal and yet not individually identifiable.

# 5.1 Creating a Safe Space

The interpretation of the photos appeared to promote gossip, personal and work-related issues, aspirations, and expressing personal and organizational values. One participant, S12, was initially shy. However, during the third round of the game, her neighbor whispered statements to her that she then uttered. Subsequently, S12 became an active participant, pulling photos before the facilitator could and playful teasing other participants. The playful elements and the unfamiliar approach appeared to help reduce staff member's concerns. Indeed, after the first round of the game, the staff member walked away from the room and came back only at the end of the session.

## 5.2 Emergent Themes

Many of the photographs concerned the crafts that the participants were making. Two primary themes emerged from this interaction: the difficulty of the crafting work and women's longing for a family or at least sociality.

5.2.1 Difficulty of Work. Several sister-survivors talked about the difficulty of learning crafting and the perseverance required to continue in the program. Describing work with needles to make necklaces, S13 commented, "I worked on *Pote* (Nepalese glass bead necklace) at the beginning and I stabbed my fingers with needles multiple times. It was hard." But she ended the comment on a more upbeat note, "Once you have learned it, it is fairly easy. We can do it working from home and could even start a business." Similar thoughts were expressed by S14, who said it took her two months time to learn the craft of making woolen shawls. She said she wanted to quit many times, but she put her "hand and mind" in a focused effort and learned slowly. S12 added, "I also didn't know

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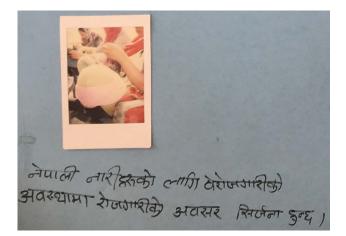


Figure 2: Sisters sitting together and spinning wool. The translated text reads "For Nepali women, in cases of unemployment, this could be an employment opportunity"

how to do it at first. My hands used to shiver. As time went by it became easier."

During the time of the study, S12 and S13 along with S15 and S16 worked together to create "hundreds of shawls" for the organization. This was tied to a kind of pragmatic discourse about future possibilities. S16 mentioned working on handicrafts as a way to augment income and make use of non-working hours: "Both [job and working at home] are important. During weekend and holidays, you could work on these [spin yarn] to learn skills as well as generate additional income."

When talking about the benefits of working on handicrafts, S14 revealed a personalized view of independence when she said, "You don't need electricity, battery, or power to use this. You don't need help from the internet. You need nothing extra for this. You could relax, talk and work instead of wasting time. If you could manage your time like this, it [spinning wool] could improve your life." This resembled but was not identical to the more institutional view reflected in the staffs' idea of "starting a business."

Mutual support was mentioned time and again. When discussing a photo of working on Saori shawl – a Japanese crotchet shawl – a survivor, S13, talked about the help other sisters provided: "... I went to learn Saori. It was fun in the beginning when others [sisters] would put the wool for us. Later when we had to put the wool on our own, it was very hard." Similarly, another survivor mentioned supporting newcomers to encourage them to participate in creating *Pote.* S12 recounted an incident of shared frustration, quipping that they had "thrown the shawl from the rooftop because we both couldn't do it [design the shawl]" (see Figure 1).

5.2.2 *Family.* Talk about crafting and sociality metamorphosed into mentions of family or at least family-like relationships. For instance, S13 while discussing a photo of the women spinning wool (see Figure 2) mentioned, "... the more yarns you make, the more profitable it is for you and you can do it from home. People could also involve their brothers and sisters in the task." She elaborated this vision, mentioning that spinning wool could provide opportunities for all family members to do something productive and "You

could talk to your friends. You could be speaking while you are also engaged in work. In cold seasons, you could bask in the sun and instead of sitting idle, you could work together with friends and family to work on this." Because Nepali people use terms like "sister" and "brother" very widely, we cannot be sure precisely what relationships were meant by this comment. However, when S14 said, "I prefer to work from home. I would have children and I would drop and pick them up from school", she seemed to be expressing a wish or longing for a family that included a nuclear component. This longing for family seemed widespread despite the fact that many of these women were sold into trafficking by their family members and were shunned after being rescued. This kind of goal never arose in conversations with staff members.

#### 6 DISCUSSION AND CONCLUSION

Our findings highlight subtle but important differences in the values and goals *of* the sister-survivors and those that have been set *for* them by the organizations they are dependent upon. Dilemmas abound, particularly about goal setting and strategy. A condition of our participation is that action must involve technology, which is a significant constraint to any goal that could be developed. PD generally favors enabling negotiation of values [16] and thereby achieving comprehensive democratic participation, but we are concerned that prioritizing the iteratively emerging voices of sistersurvivors may put them at risk, especially if their directions require side-stepping and possibly alienating the NGOs. The circumstances of the sex trafficking survivors both underscore the on-going importance of PD and add to the list of concerns and reasons that not all aspects of all processes should be PD.

Pragmatically, we face at least three choices: we could go in with a small intervention designed to create the least disruption possible and see what happens; we could respond directly to the voices of the sister-survivors by supporting connections between them after they leave the protected living context; or we could respond to the driving theory of the NGO's by focusing on supporting crafting. All of these can be done in a way consistent with PD.

We believe that we need more data about the lives and the values of the sister-survivors in order to take design action. The larger facts of the Nepali context and the smaller findings from talking with sister-survivors must be put into a relationship with one another in crafting next steps. We know that the sister-survivors depend on the NGO's, but we do not know whether the crafts that they learn while living in protected circumstances have enduring potential. The social relations that develop while in the protected living situation may have a potential for lasting impact but may not be an adequate substitute for a sense of family.

The enduring question of all design is "How do we recognize the right thing to do?" Sometimes PD can answer this question, but that doesn't mean that it relieves us of moral responsibility. We believe that the rule that must guide our behavior is that of holding onto the ambiguities that we have uncovered while engaging in gentle explorations of conditions and behavioral directions. We argue that when a population is so vulnerable, we must live with ambiguity, prioritizing understanding the implications of our choices over our natural impatience and eagerness to take action. Participatory Tensions in Working with a Vulnerable Population

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