Research with Syrian Refugees in Rural Lebanon: Ethical Considerations

Reem Talhouk

Open Lab

Newcastle upon Tyne, UK

R.R.Talhouk2@newcastle.ac.uk

Anja Thieme

Microsoft Research

UK

anthie@microsoft.com

Abstract

As the Syrian refugee crisis escalates researchers are taking on a larger role in exploring how to address the problems this marginalized population is facing. The high penetration of mobile phone usage among refugees opens opportunities for HCI to address issues such as access to antenatal care. However, our experience working with Syrian refugees residing in Lebanon surfaced several ethical considerations. Issues regarding remuneration, researchers' roles, deprivation and informed consent arose. These are issues that researchers should account for in their research design and in the training of the research team. They also call to question the institutionalized ethical procedures that may not be easy to apply in this context.

Author Keywords

Ethics; sensitive settings; marginalized communities.

ACM Classification Keywords

H.5.3 Group and Organization Interfaces

Introduction

When we, as HCI researchers, attempt to maintain the autonomy and respect for participants we typically follow fixed ethical guidelines or procedures such as informed consent. However, even when obtaining approval from local ethical boards that account for various ethical challenges, such as different cultural norms, researchers can be exposed to unforeseeable situations. These engagements make us question the

Key Study Findings

High usage of Whatsapp:
The research identified a high penetration of smartphones and high usage of Whatsapp among the Syrian refugees providing rich opportunities for technology design.

Ranging literacy levels:
There are large variations in technological skills, in the languages spoken, or abilities to read or write.

Social norms: Social and familial structures are hierarchical in nature. Husbands would not discuss issues related to Antenatal Care (ANC).

Trust: For advice, women refugees would turn to the sheikha, an older woman within the community.

Health Beliefs: Women believed that an effective doctor is a doctor that prescribes effective medication.

effectiveness of our current procedures. In this paper, we describe some of these unforeseeable situations that we encountered in our in-situ engagements with Syrian refugees residing in Informal tented Settlements (ITSs) in Lebanon. In discussing how we responded to the issues that arose, we seek to debate examples of best practices to inform future research involving vulnerable communities.

Female Syrian Refugees in Lebanese ITSs
The current crisis in Syria began in March 2011, and has led to citizens fleeing Syria in search of safety. Lebanon is a small middle-income country neighboring Syria. Despite the country's limited resources, there has been a huge influx of more than one million refugees [6] across its borders. The Lebanese Syrian refugee policy has banned the establishment of official Syrian refugee camps. This has left 82% of the refugee population living in urban rented housing and 200,000 living in Informal Tented Settlements (ITSs) [19]. The 1,200 ITSs are scattered across the rural area of the Bekaa region, where refugees rent land and set up tents [19]. The dispersion of the Syrian refugee population has translated into refugees residing in areas of varying economic opportunities, resources and access to services [33]. The strain on resources has resulted in tensions among Syrian refugees and their Lebanese host communities [8].

The United Nations High Commissioner for Refugees' (UNHCR) Health Working Group in Lebanon has highlighted a gap in antenatal care (ANC) service provision. Only 20% of female refugees were meeting their target for ANC visits during the first half of the year 2015 [3]. Major barriers to utilization of antenatal care were identified as being: cost of healthcare,

transport to healthcare facilities, and lack of female healthcare providers [5]. ANC services are not only important to the health of the mother, but continuity of ANC has been shown to improve neonatal mortality. Additionally, the United Nations High Commissioner for Refugees (UNHCR) and its partners have indicated that early marriages among the Syrian refugee population is on a rise [9]. Early marriages are often used as a coping mechanism by families to relieve themselves of financial burdens.

In light of these challenging health circumstances for refugees, two Arabic speaking researchers conducted five focus groups in different ITSs with a total of 55 Syrian refugee women. They aimed to explore and investigate the feasibility and acceptability of incorporating technology into the provision of ANC for refugees in rural Lebanon. The aim was to account for the refugee women's health beliefs, health experiences and their social networks when exploring the use of technology.

The ITSs were selected based on a landscaping exercise done with healthcare providers working in the Bekaa area of Lebanon. The exercise indicated which ITSs Primary Healthcare Clinics (PHCs) are aiming to cater to, the size of the ITSs and the safety level of the ITSs for the researchers to visit. The five different ITSs were picked to reflect a variation in economic status of refugee families and usage of healthcare facilities.

Ethical Concerns that Arose In-Situ
Conducting these studies in the ITSs placed the researchers in engagements that raised several ethical concerns. These were related to issues of: (1) participant remuneration and informed consent; (2)

Key Study Findings Continued

Perceptions: The women perceive that healthcare providers are discriminating against them, and this is a main challenge to overcome.

Opportunities for Design: Possible designs for this population include conventional infrastructure for transportation logistics and appointment making, better communication with healthcare providers (possibly through peer networks) and digital media-for health advocacy.

assumptions made by participants that were difficult to negate; and (3) respecting cultural norms while maintaining ethical research principles. Additionally, our work in the field gave us insights on possible future ethical concerns for researchers to consider when engaging with this or similar communities.

Benefits to Participation: What will we get out of this?
A report by the International Labor Organization stated that the majority of Syrian refugees in Lebanon are living in hard socioeconomic conditions [4] with 70% of households living below the poverty line of US$3.84 per person per day [8]. Therefore, in our ethics evaluation we considered whether any type of remuneration for participants' time would be considered coercive and place undue influence. This is because even a minimal payment or remuneration would be of very high value to the population; therefore, women may feel obliged to participate in order to not lose the opportunity of gaining resources, as small as they would be. Consequently, we held discussions with the local ethics board. We came to the conclusion that any type of remuneration would have been considered to be coercive. Additionally, we considered that the study was not a deployment study that would require follow up, therefore participants would only engage in the research once for one to two hours. Furthermore, our presence did not hinder participants from going to their daily jobs as we visited the ITSs after the typical working hours. We did not foresee any challenges arising from this decision as the researchers had had experience conducting exploratory studies with refugee populations before. However, one main challenge regarding remuneration did arise and it was due to the method in which we accessed the population.

To access the population, the Lebanese Ministry of Public Health (MoPH) obliged us to be accompanied by a social worker. This provided the research team with a safety measure as the social worker is familiar with the community. The social worker's connection with the community aided in building rapport with the participants, but his presence elicited certain expectations by potential participants. This is because he typically provides services and/or benefits to members of the community. These are usually in the form of services and/or supplies. Therefore, despite our efforts to clearly state, as part of our informed consent process, that participants will not receive any type of remuneration, this was still expected by some of the participants. Midway through the focus groups, participants would ask 'What are we getting out of this?'. Three of the participants, who had voiced this concern, left the focus groups before its completion. At each such instance we restated that there will be no direct benefits, in the form of services or money, given and that participation is voluntary. The recurrence of these incidents called to question whether the consent process was overshadowed by the presence of the social worker. Furthermore, it invited reflections on how to better configure our consent process to counter-balance and address such mis-conceptions that were invited through the presence of this gatekeeper. Since we can not change the method of accessing the population, considering policies placed by the MoPH, we are looking in to ways to address this challenge. One of the solutions being discussed is providing benefits in the form of health education to the whole ITS visited regardless of whether women of that ITS choose to participate or not.

Researcher Role Conflicts: What medication can I take?
The researchers conducting the focus groups were affiliated with the American University of Beirut Medical Center, which is one of the most renowned hospitals in the Middle East. The medical center has several mobile health clinics visiting the refugee ITSs. This created expectations from participants that the researchers possessed medical knowledge. Consequently, in every ITS we visited, participants would persistently hand us the results of lab tests and prescriptions, asking for medical advice. We explained that we are not qualified to give medical advice. Participants also asked us to read out to them hand written prescriptions given to them by their doctors. They explained that they can not read or write and do not know whether they should continue taking their medications. We did attempt to silently read the prescriptions to ourselves before considering reading them to the participants, however the majority of the times we were unable to read the doctor's handwriting. Furthermore, some of the prescriptions were in French and none of the field workers are fluent in French. Therefore, we questioned whether we should read out the hand written prescription to participants of low literacy. This was due to fear of being held liable for any miscommunications or mistakes related to the illegibility of the doctors' handwriting. In response to these situations we emphasized that participants should follow up with their healthcare providers.

Witnessing the dire living conditions of the participants and their health problems that are persisting due to lack of trust between them and healthcare providers, made us as researchers feel that we should be doing more to help. After being bombarded with health questions, one of the researchers who is a registered dietician licensed to practice in Lebanon felt obliged to answer nutrition related questions. Although this was not part of the research plan and was not present in the consent script, the fact that the participants were not receiving any benefits made her feel guilty. Therefore, she gave advice regarding boiling water and milk before consuming it, cheap high protein foods, and the benefits of breastfeeding.

Both the above mentioned incidences highlighted how in these versatile in-situ situations, lines between being a researcher and a healthcare provider become blurred. This makes it difficult for researchers to follow what was agreed upon in the consent process. Especially when they feel that the participants would benefit from their expertise with no increased risk to participants. These incidents were reported to the principle investigator and it was agreed that as researchers working with this community health education will be integrated in to all their future exploratory research projects.

Deprivation: You can not leave without taking these?
Another instance in which we found ourselves uncomfortable was on departure from one of the ITSs. This particular ITS is situated on farming land on which the men of the community worked. Before leaving, a group of community members presented us with two large baskets of peaches. This was a very important gesture being made by the community as part of their act of hospitality. We were in a position where, rejecting the baskets would be considered culturally rude by the community. On the other hand, accepting them felt inappropriate as it is a source of income for this extremely financially deprived community. These concerns were further amplified by our awareness of

the fact the participants did not receive any immediate benefits or remuneration from the study. The issue was resolved by us taking only some of the peaches they were trying to give us. Acts of hospitality such as this were something we had not foreseen. Therefore, the research team wasn't prepared with how to respond. This is also an issue that is up for discussion in future work with the ethical review board.

Risk of Excluding People: Who to consent?
In this initial study our exclusion criteria was refugees under the age of 18. This criterion was set because the sampling population includes girls in early marriages, below the age of 18. If this exclusion criterion was not present, then the researchers would have faced ethical dilemmas regarding consenting participants below the age of 18. In most cases the girls' families (i.e. Fathers or mothers) do not live in close proximity or even in the same country as them. This would considerably complicate including them as their guardians in the consent process. Furthermore, culturally, rather than the parents, the community considers the girl's husband to be her guardian. Including their husbands in the informed consent process would have made us uncomfortable, because in some cases the husband is also a minor and because of our own personal principles regarding early marriage.

We are currently in the stage of designing deployments to improve maternal and reproductive health amongst this community. The concern that we as researchers are debating is whether we should maintain the same exclusion criteria. Maintaining it would be at the cost of benefiting girls in early marriages. We should also consider that the close knit nature of the community within the ITS may entail isolating community members

excluded from the study. This would decrease the researcher team's rapport with the population.

In a way to address this the researcher team is going to open a dialogue with the local ethics board to discuss this issue. We are going to explore the argument that if the potential participant is considered by her community to be able to bear the responsibility of taking care of children and a family, then she can be deemed capable to weigh the risks and benefits of participating in a research study. Similar to a potential participant above the age of 18. Additionally, we are discussing obtaining parental consent through phone calls.

Conclusion
Engaging with this population highlighted several concerns related to working with a marginalized community that is set in its social norms, interactions with NGOs and expectations from the researchers. The issues that arose questioned how much of our formal methods of maintaining ethics in our work can be extended to these situations. Furthermore, it calls to critically consider how our processes of conducting research ethically in these contexts should be adjusted to address issues such as early marriage and extreme poverty.

References
[1]   Benage, M. et al. 2015. An assessment of antenatal care among Syrian refugees in Lebanon. *Conflict and Health*. 9, 1 (2015), 1–11.

[2]   Beyond Reform & Development 2013. *Preventing Tensions and Improving Quality of Services for Syrian Refugees and Lebanese Host Communities*.

[3]   Kassem, A. et al. 2015. *Mid-Year Dashboard*.

[4]   Masri, S. and Srour, I. 2014. *Assessment of the Impact of Syrian Refugees in Lebanon and Their Employment Profile*.

[5]   Reese Masterson, A. et al. 2014. Assessment of reproductive health and violence against women among displaced Syrians in Lebanon. *BMC women's health*. 14, 1 (2014), 25.

[6]   Syria Regional Refugee Response: 2015. *http://data.unhcr.org/syrianrefugees/country.php?id=122*. Accessed: 2015-09-22.

[7]   UNHCR 2015. *Independent Programme Evaluation (IPE) of UNHCR's Response to the refugee influx in Lebanon and Jordan Independent Programme Evaluation (IPE) of UNHCR's Response to the R efugee Influx in Lebanon and Jordan Beyond Humanitarian Assistance ? UNHCR a*.

[8]   UNHCR - Greater support in countries of first asylum needed to stem refugee outflows: 2015. *http://www.unhcr.org/55ddd2c86.html*. Accessed: 2015-12-15.

[9]   Sexual and gender - based violence prevention and response in refugee situations in the middle east and north africa.