Syrian Refugees and Digital Health in Lebanon: Opportunities for Improving Antenatal Health

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ABSTRACT
There are currently over 1.1 million Syrian refugees in need of healthcare services from an already overstretched Lebanese healthcare system. Access to antenatal care (ANC) services presents a particular challenge. We conducted focus groups with 59 refugees in rural Lebanon to identify contextual and cultural factors that can inform the design of digital technologies to support refugee ANC. Previously identified high utilization of smartphones by the refugee population offers a particular opportunity for using digital technology to support access to ANC as well as health advocacy. Our findings revealed a number of considerations that should be taken into account in the design of refugee ANC technologies, including: refugee health beliefs and experiences, literacy levels, refugee perceptions of negative attitudes of healthcare providers, and hierarchal and familial structures.

Author Keywords
Refugees; Lebanon; Syria; Antenatal health; Maternal health; Digital health

ACM Classification Keywords
H.5.3 Group and Organization Interfaces.

INTRODUCTION
The United Nations High Commissioner for Refugees (UNHCR) estimates that there are 13 million refugees worldwide [35]. Refugee populations experience many disadvantages, including higher health risks due to disintegration of health and social services [25]. Studies have shown that pregnant women in refugee contexts are at increased risk of fetal death, low birth weight, caesarean section, and antenatal complications [2,17]. Acknowledging the need for humanitarian aid innovation, the UNHCR and NGOs now advocate for the use of technology to support refugee health needs [18,31].

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Against this background, our research explores the feasibility and acceptability of incorporating digital technology into antenatal care provision for Syrian refugees in rural Lebanon. It aims to contextualize the use of technology with the health beliefs, health experiences, and social and health networks of refugees in need of ANC. While most technologies for refugee health are designed for use by healthcare providers [11,32] , previous research also identified a high use of smartphones and communication applications such as Whatsapp among refugees [38], which affords an opportunity to empower refugees in their antenatal health through digital interventions. To this end, we investigated opportunities and factors that can meaningfully inform technology design for antenatal health in the context of this marginalized community. Our findings of a focus group study involving 59 women refugees show that such designs should account for contextual and cultural understanding of refugee health beliefs and experiences; literacy; refugees' negative perceptions of their healthcare providers; as well as community hierarchies and current communication practices. We present these factors with the aim of providing an empirical basis for the design of digital technologies that respond to one of the most pressing humanitarian crises of recent times.

RELATED WORK
The utilization of digital technology by both refugees and humanitarian aid providers has been increasing [13,16]. Although Baranoff et al. [5] found that newly settled refugees in the United States (in 2014) mostly used feature phones, by contrast, Ying et al. showed that over a similar period Syrian refugees, settled in Jordanian camps, are using smartphones both to communicate with each other and to access Facebook for camp updates [38]. Several platforms aim to increase engagement of refugees and their access to information, with the majority of these targeting specifically younger refugees. For example, in Jerusalem, Sawhney [31] describes an initiative for Palestinian youth to creatively express themselves through digital story telling. Similarly, Yerousis et al. [39] established a computer club in refugee camps with the aim of strengthening social ties among Palestinian refugee youth in which university students would conduct capacity building exercises for the youth through informal computer learning. Digital role-playing has also been used in host countries to

enhance the inter-cultural empathy of refugees entering schools [3].

In terms of promoting and supporting refugee health, a small number of initiatives have given healthcare providers language translation tools to facilitate patient-clinician interaction [11,32]. Baranoff et al. [4] used Near Field Communication (NFC) tags to support refugees to familiarize themselves with their new surroundings. For example, in hospitals, the tags helped refugees using feature phones to find their doctor's office and automatically updated caseworkers that appointments had been attended. Previous interaction design studies for refugee communities also emphasized the importance of understanding the specific context of refugees [4,26,28]. This includes exploring refugees' situational contexts as well as their communication practices and habits (indeed their primary source of information is often more experienced refugees) [4,28]. Furthermore, the potential wide range of technology literacy should also be considered [26]. However, despite a small number of isolated case studies[4,38], refugees' existing technology capacities, health experiences and knowledge have been largely under-explored, and antenatal health of refugees in particular presents a new area of research in HCI and digital health research communities.

Some inspiration can be drawn for designs for refugee health from other resource constrained settings, such as work done in developing countries with marginalized communities. Ramachandran et al. [28] provided social workers with persuasive health messages on their phones to be used during counselling sessions. In similar contexts, community-led video education systems allowed social workers to compose locally relevant health education videos [19,24] which can then be viewed by women in the community. Tiwari and Sorathia [32] used an audio visual application that allows mothers of low literacy to call for emergency services and identify, through pictures, their health problems. Audio recorded advice would then be sent accordingly. SMS has also been used to send bulk messages about maternal health to women, for example, by allowing clients to send messages to a nurse who would then respond with more personalized messages [27]. Additional systems have been designed to support social workers in identifying high risk pregnancies, including a mobile phone application that allows data collection, such as registration information for new cases, and follow-up meetings between social workers and women in rural areas [2]. Such designs have generally focused on supporting social workers to prioritize clients and the advice needed on how to proceed with the patient's care [2,21,33]. However, existing systems have largely focused on the perceived needs of healthcare workers. The use of digital platforms to enable peer support amongst refugees, or interactions between refugees and members of other communities remain unexplored.

SYRIAN REFUGEE ANTENATAL CARE CONTEXT

The Syrian crisis began in March 2011 and has led to citizens fleeing Syria in search for safety. Lebanon is a small middle-income country neighboring Syria. Despite Lebanon's limited resources, there has been a huge influx of refugees (over 1.1 million) across its borders [36]. Consequently, the Lebanese education, health and economic systems are struggling to cater to both populations [9]. The Lebanese Syrian refugee policy has banned the establishment of official Syrian refugee camps, therefore leaving 200,000 Syrian refugees living in informal tented settlements (ITSs) [17]. The 1200 ITSs are scattered across the rural area of the Bekaa region, where refugees rent land and set up tents [17]. The strain on resources has resulted in tensions among Syrian refugees and their Lebanese host communities [6].

Female Refugees and ANC

The Syrian refugee population accesses healthcare through Lebanese primary healthcare centers (PHCs) [34]. There are currently 213 PHCs within the Ministry of Public Health (MoPH) network [10]. PHCs function under the umbrella of the MoPH but are owned and managed by separate entities. PHCs exhibit significant variation in level of resource and capacity, and thus the quality and cost of the services they provide [5]. The UNHCR's Health Working Group in Lebanon has highlighted a gap in ANC service provision. Only 20% of the group's target for ANC visits during the first half of 2015 was met [17], and Benage et al. [6] found that refugees residing in the Bekaa region accessed fewer ANC services than those in other areas of Lebanon. Major barriers to utilization of ANC services were identified including the cost of healthcare, transport to healthcare facilities, and lack of female healthcare providers [30]. The difficulties humanitarian agencies are facing in improving access and utilization of ANC services has resulted in ANC becoming one of the UNHCR's priorities.

Refugees and Technology

An accurate (and current) assessment of technology adoption and use by Syrian refugees in Lebanon is difficult to establish. However, Internews [14], a media development organization, has reported that refugees are heavy users of mobile communications including SMS and Whatsapp. This report also highlighted that implementation problems of the humanitarian SMS systems make refugees hard to reach via digital communications. These problems included inaccurate number directories, failure to take account of phone sharing, and the lack of phone network coverage in some areas. Additionally, humanitarian agencies are experiencing barriers in communicating health information due to low literacy rates among the refugee population in Lebanon. To our knowledge, current statistics on literacy rates among Syrian refugee women of reproductive age in Lebanon are non-existent.

METHODS

Understanding the factors that impact women's access to and knowledge of ANC in the challenging contexts that

refugees typically find themselves is a significant endeavor. In our study we aimed to explore how Syrian refugees in Lebanon are already using digital technology as well as new design possibilities to support antenatal health within their communities. In particular, our research sought to understand the contexts in which Syrian refugees in rural areas access technology and how they use it in communication. This further involved investigations of aspects of feasibility, acceptability, and preferences of Syrian women in relation to the technology use to access ANC. We chose focus groups with women refugees as our primary method for data collection, which presents a well-established and widely used method amongst this population, as the women commonly feel more comfortable discussing issues related to their health amongst each other. The study obtained all necessary ethical approvals from The American University of Beirut and Newcastle University.

Landscaping Exercise

Given the complexity of the healthcare and humanitarian aid system, a landscaping exercise was conducted to better understand: (1) the existing healthcare system providing ANC services to Syrian refugees and (2) the technological capacity and capability of our subject group (on which any digital ANC intervention would depend). The process involved semi-structured interviews with key informants and healthcare providers catering to the Syrian refugee population in Bekaa. The findings of this phase of the study informed the design and contextualization of the research undertaken with the Syrian refugees described here. Key findings of the landscaping exercise guided the formulation of the refugee focus group topic guides. As a result of discussions with PHC administrators, we were able to identify five ITSs to visit and that the MoPH recommends four ANC visits during pregnancies. From discussions with our key informants we also identified three key issues of concern to them: (1) a significant variation in level of ANC attendance, with some refugees visiting more frequently than they are required, and others not coming at all; (2) the high numbers of patients visiting the clinics posed a capacity challenge for PHCs; and (3) low health literacy levels of refugees. As a result we configured our engagement with the refugees to explore these issues further.

Recruitment

Syrian refugee women and their husbands were recruited from Syrian refugee communities residing in ITSs in the Bekaa region of Lebanon. The community leader, or "*shaweesh"*, was contacted in order to gain access to the women and their husbands. The *shaweesh* is typically a man that negotiates the establishment of the ITS with the land's property owner (with a view to ensuring price stability and managing payment of the rent). The *shaweesh* only played the role of a gatekeeper, who contacted the women and offered his tent for the focus group as it was typically the most spacious. He did not attend any focus groups with the women. A total of six focus groups (55 women and 4 men) were conducted, in five ITSs visited. We had anticipated higher participation by men, yet despite our best efforts we were largely unsuccessful in engaging them. Therefore, in the case where only one man in an ITS agreed to take part in the study (C2 below), we conducted a semi-structured interview with him alone using the same topic guide as was used for the focus groups. We could not involve him in the women's focus group because culturally, issues of maternal and antenatal health are not openly discussed between people of the opposite sex.

We did not collect demographic data as conducting the focus groups was unavoidably fluid. Some participants joined midway through sessions, and others left early to check on their children. We were, however, able to distinguish that one older woman usually took on the role of the "*sheikha*" (denoted as 'S' in Table 1). The *sheikha* is deemed to be the female leader, or "the wise one", who women would seek out for guidance and support.

Focus groups

The focus group discussions explored women's health experiences during their visits to PHCs and their current use of technology. Additionally, we discussed different ways they envision using technology to improve access to ANC services and support health education. These discussions were open-ended and participants were encouraged to talk freely on these and other related topics. Native Arabic speaking researchers conducted the focus groups in Arabic. Two researchers attended each focus group, one would guide the focus group while the other observed and took notes.

Informal Tented Settlement	Walking distance to PHC (mins)	Number of participants	Participant code
C1	30	11 women	C_1S, $C_1W_1 \ldots C_1W_{10}$
C2	30	1 man 15 women	C_2M_1 C_2S, $C_2W_1 \ldots C_2W_{14}$
C3	90	10 women	C_3S, $C_3W_1 \ldots C_3W_9$
C4	35	4 men 6 women	$C_4M_1 \ldots C_4M_4$ C_4S, $C_4W_1 \ldots C_4W_5$
C5	60	13 women	C_5S, $C_5W_1 \ldots C_5W_{12}$

Table 1. Each participant was given a code denoted as C_XW_Y, where X is the number of the ITS visited and Y the number given to each woman (W) or man (M). S is the sheikha.

Data Capture & and Analysis

All focus groups were audio recorded and translated and transcript from Arabic to English. Thematic coding and analysis was carried out, which was supported through NVivo 10. The analysis relied on data coding and a constant comparison between codes to identify recurring themes. Data that was initially coded was revisited until it was clear that no new themes emerged [12]. Codes that have common elements were merged to form categories that were then clustered around each major theme. The analysis and interpretation of the data is further informed and contextualized by the researcher's own experiences of the setting and the conduct of the focus groups.

Ideation Artifacts

Two ideation artifacts, or probes, were designed to actively engage the women participants in discussions and to support their imagination of ideas as to how technology might be used to provide ANC services. Mindful of the low literacy levels of this refugee population, the artifacts were pictorial in character with minimal writing. The first probe was a set of trump cards (Figure 1) used to identify how they would prefer to: (1) be contacted by healthcare providers; (2) contact healthcare providers; and (3) access health information. Options included booklets, phone calls, text messages, peers, and social workers.

Figure 1. Pictorial set of trump cards used to discuss with the women how they would prefer to communicate with healthcare providers and to access health information

The second probe was a booklet (Figure 2) containing images intended to convey health information regarding pregnancy. Alongside the booklet we provided a digital voice recorder which we encouraged participants to use to enact recording their symptoms, pregnancy experiences, patient information, and instructions that patients could follow. Our aim in using such an artifact was two-fold. Firstly, to explore communication problems refugees face with healthcare providers; and secondly, to initiate discussion on the use of technology within a peer network or support group. However, in the *Discussion* and *Limitations* sections, we explain how and why participants did not make full use of these probes.

FINDINGS

The data collected provided rich insights into the Syrian refugees' community and healthcare context, and contain detail especially on the population's current utilization and experiences with ANC services and technology. The discussion of health and technology further enabled a better understanding of the interplay between refugee women's health beliefs and experiences as well as their use of technology for antenatal health.

Figure 2. A pictorial booklet conveying antenatal health information with an attached voice recorder that women could use to enact recordings of symptoms and pregnancy experiences, patient information, and health instructions

The context in which the refugees were living and accessing healthcare information and services was found to include hierarchies and social networks that shape their communication patterns and their health choices. Additionally, we discovered the interconnectedness between participant's use of technology and the refugees' health beliefs and experiences. Across all focus groups, mobile phones were clearly the most utilized technology. Participants reported that all refugee households owned at least one mobile phone, and that most of these were smartphones. Therefore, the majority of focus group discussions centered on the pivotal role of mobile technology in participants' day-to-day lives. Mobile phones allow refugees to maintain contact with family members in Syria and, to some extent, are used to facilitate their access to healthcare and humanitarian aid. Our findings also provided insight into potential barriers to engaging the Syrian refugee population in design activities, including issues related to the participation of men, and the use of artifacts to support discussion and ideation.

Family, Hierarchy & Social Network Influences on ANC

Our experience of accessing this marginalized population had a number of implications. To gain access to the ITSs we applied for security clearance from the responsible governmental institutions. Additionally, a representative of an NGO contracted by the Ministry of Public Health accompanied us at all times. Despite initially explaining to the refugees that direct benefits or remuneration would not be provided in return for their participation, the presence of the NGO employee led several women to believe that they would. Consequently, some women withdrew midway into focus group discussions once it was reiterated that no direct benefits would be given. This sometimes interrupted discussion flow.

In order to have access to participants, their community leader, the *shaweesh*, was contacted by the NGO representative. However, in relation to communicating with the women, the *shaweesh* played only a small role. He only requested that the women meet at his tent where the focus

group would be held. From social encounters such as these, that we experienced in all the settlements we visited, it was evident that the women have strong local social networks. Teamwork, friendship and family were key elements of the community's social networks. Throughout the focus group discussions, the importance of social hierarchy within these networks was readily apparent, with each settlement having one woman who was referred to as the *sheikha*. The *sheikha* is deemed to be "the wise one" and, as the woman that others would consult for guidance and support, she would often dominate group discussions despite active efforts of the facilitators to involve all women equally. The influence of the social networks on health choices and behaviors were manifested through advice giving, health care provider selection, favor exchange among the women, companionship, and literacy peer support. The women would seek the *sheikha* for advice regarding their pregnancies and other health related issues. Additionally, participants reported sharing their experiences with different healthcare providers amongst themselves, and decided on which healthcare provider to use accordingly. About her choice of a healthcare provide, one woman explained that it "*depends on what we hear from others"* [C_2,W_5]. The women would sometimes rely on their relatives and neighbors for favors when visiting healthcare providers. Another woman shared: *"My daughter asks her neighbor to keep her daughter with her"* [C_1W_8]. The women would accompany each other to the PHCs and those that are more literate would help others read prescriptions and medicine related pamphlets.

The participation of men in the study was low. Only 5 men in total agreed to participate, even though field visit times were rescheduled to the afternoon, when men would be back from their work. The men did not respond to the *shaweesh*'s invitation to participate in the focus group. We observed, while carrying out the single focus group discussion with men, that male participants exhibited avoidance and reluctance to discuss ANC and family planning. They shifted their body posture away from the researcher conducting the focus group, avoided eye contact, and responded with curt answers. This discouraged further probing. However, we were able to probe the role men played in antenatal health through discussions with the women participants. It was found that the husband plays a primary role in family planning; he decides when it is a suitable time to have children and whether his wife should use contraceptives. Male contraceptives were not used as it was generally accepted that it is the woman's responsibility to obtain contraceptives. Contraceptives being used included intra-uterine devices and birth control pills. The husband also plays a role in advising his wife on which doctor to go to, based on what he has heard regarding the doctor's reputation from his own social network. Only two women informed us that their husbands accompanied them to the clinics, who were perceived as *"modern men"* [C_1W_7] by the other women. Additionally, depending on their current financial situation, men decide whether or not women should go to a private doctor.

Insights into Current Digital Technology Use

The majority of the women and men reported that each household owns at least one mobile phone. The husband or eldest son usually holds the mobile phone, therefore, the women access the phone during the evenings when the men return from work. Despite low literacy skills, the women reported to frequently access mobile communication applications, mainly Whatsapp, which was used by the majority of women to communicate with their families.

The high usage of Whatsapp among the Syrian refugee population was attributed, by the women, to: (1) the high popularity of the application within the region; (2) the maintenance of the landline phone and internet network, even in areas where there is no cellular reception, has made internet-based communication prominent; and (3) the fact that compared to traditional cellular communication in Lebanon, communication through mobile-based applications such as Whatsapp comes at a lower cost. The majority of the population purchases pre-paid cellular lines with Whatsapp bundles provided by the service providers. The two cellular service providers in Lebanon provide the bundle at a cost of $4 (US dollars) per 200 MBs per month. Additionally, most refugees reported that they pay a monthly fee of $7 to connect to a Wi-Fi network. The network is usually owned and managed by a refugee and provides unlimited Internet and Whatsapp access. Despite the network being described as *"very slow"* [C_5W_4] refugees reported subscribing to it. A few also accessed Whatsapp through Wi-Fi and cellular service providers, as one respondent said, *"When we are here in the settlement, we use the network and when we leave we use 3G"* [C_5S].

Voice Notes Vs. Text Messages Vs. Images

A popular Whatsapp feature used by refugees to communicate is the voice note, whose use was preferred to texting by the majority of women. This aspect was found to be dependent on both language literacy and technology literacy. Since all the settlements we visited were home to refugees coming from rural Syria, literacy levels among the female population was generally low. Out of the 55 women participating, only 7 voluntarily indicated that they were literate (without us directly questioning participants' literacy levels). As one woman explained, *"most of us do not know how to write so it is better with voice notes. It is better for us"* [C4,W_5]. This behavior was common to all of the five settlements we visited. One respondent who was literate indicated that technology literacy plays a role in encouraging the use of voice notes. She clarified that, *"I'm not quick in typing, so I prefer to send voice recordings"* [C_2,W_5]. Despite the preference for voice communication, utilization of free call services provided by web-based mobile applications was not common. This was due to the low connectivity and speed of the Internet connections available to them. Sending and receiving images was also

uncommon among the women. We observed slight discomfort among some when discussing the possibility of sending images as part of a health communication exercise with concerns being expressed regarding who would view such images.

Group Messaging

Despite the high usage of Whatsapp, the creation of Whatsapp groups was not popular. One woman indicated that only *"some of us [are in Whatsapp groups]"* [C_1W_1]. One settlement that has benefited from the aid of a humanitarian agency in setting up an internal governance committee uses a Whatsapp group to schedule meetings and discuss urgent matters. One of the women described as one of the benefits of using Whatsapp groups to be able to coordinate with her neighbors organized carpools and market visits. She reported that, *"My friend would tell me [on the group], send your daughter to watch my babies I want to go to the market"* [C_1W_2]. Some women found Whatsapp groups to be very time consuming, as one woman explained: *"There are some people that are free to do these things, but others for example, like us have things to do, look after the children, take care of our responsibilities"* [C_2W_3]. Another woman believed that a Whatsapp group would be a dangerous distraction from her children as *"I have one very naughty girl, she would [literally] burn the tent down"* [C_2W_3].

Connecting Refugees to Each Other

When asked how Syrian refugees are using their mobile phones, both male and female respondents were quick to answer that their primary use is to *"talk to our families and parents, to know about their news and situations"* [C_1W_1]. While some women within the same settlement described how they used mobile phones to communicate with each other, many explained that living in close proximity with each other makes it unnecessary to use mobile phones to communicate with neighbors, saying, *"no… we talk amongst ourselves"* [C_5W_{11}]. Literacy also played a role in either expanding or restricting the variety of mobile applications used by the women. Some reported using a wider range of communication and social media applications but an older woman indicated that this practice is only common among younger language literate women.

Insights into ANC Experiences, Behaviors and Beliefs

The ITSs visited varied in their location and resources available. The settlements were all situated on uninhabited land, with only two of the five ITSs located close to the PHCs that cater for refugees. This led to a variation in PHC follow-up frequency among the women from different settlements. Women living near the PHCs visited clinics more frequently with some of them going *"once or twice a month"* [C_3W_2] throughout their pregnancy. Access to transportation vehicles owned by male relatives, such as motorbikes, was also reported to increase the frequency of follow-up visits. Those living in more isolated settlements reported that they visit the doctor at the beginning of their pregnancy and around the time of the expected delivery date. They would only follow up with their gynecologist if *"something is wrong"* [C_5W_5], or if they have a history of miscarriages. The women in isolated ITSs would walk for up to 90 minutes together, and sometimes with their children, to reach the closest PHC. The women further elaborated that the PHCs do not have an appointment or reminder system and therefore it is up to them to decide when to follow up with the doctor. They also identified financial constraints as one of the biggest barriers to accessing healthcare. A *sheikha* from one ITS stated that even though ANC is subsidized at $3 per visit, *"most people do not have the ability to pay that much"* [C_2S]. This lack of follow-up contrasted with the ANC practices of the women reported in pre-war Syria, where they followed up with healthcare providers once per month. The changes in behavior are attributed to changes in the participants' health environment (appointment system and healthcare costs). Describing the healthcare system in Syria before the war, the women highlighted that *"they gave us a card with a list of all the appointments"* [C_4W_3] and that ANC was cheaper because *"[we] used to pay once and did not pay for the follow ups. No matter how many times you follow up they don't take money"* [C_2W_7].

Refugees' Perceived Attitudes and Health Behaviors

The participants' experiences of healthcare services in Lebanon, reinforced some of their health behaviors. While discussing their experiences of the healthcare system, participants described healthcare providers based on their perception of the healthcare provider's attitude towards them. They elaborated that their positive experiences included interactions with healthcare providers that would take their time during the visit to explain to them their health condition and prescriptions. Positive interactions also included instances of respectful communication. Negative experiences included interactions with doctors that would not give participants time to talk during consultations (described as being due to the high volume of patients in the waiting room). One woman said that the healthcare provider *"did not give me the option to talk to him, they don't give us any attention"* [C_2W_5]. The importance of good face-to-face communication with healthcare providers was further reiterated by some women who explained that "*if a woman does not go to the doctor and explain to her [about her condition]…assesses her, it would not work especially since she is pregnant"* [C_2W_2]. The women also recounted incidents where they perceived that the healthcare providers showed a negative attitude towards them with one woman recounting feeling offended when a nurse said to her *"Oh you are Syrian, I can't believe how many kids you have"* [C_3W_{10}]. The women elaborated on their perception of healthcare providers not prioritizing refugee wellbeing in relation to not providing them with appointments and making them wait to see a doctor. One *sheikha* described how she once "*sat and waited [from 7:00 a.m] til 9:00 a.m for them to come and open the clinic and*

then they make you wait until 10:00 10:30 for them to start giving you a place in the queue" [C_2S]. Another woman described a stressful encounter that resulted from a miscommunication with a nurse. She had attended the clinic early in the morning regarding severe bleeding she was experiencing during her pregnancy and *"I told her I am not sure how the appointment system works... She made me wait till the last appointment and then at the end she tells me why are you coming now! [so late]"* [C_5W_8]. The perception of negative attitudes towards refugees has led some women to not access particular healthcare providers so as to avoid such negative engagements. The women in one ITS all agreed that they would rather go to a PHC that is further away to avoid the perceived negative attitude of the healthcare providers at a closer clinic. Two participants described how their distressing experiences have led them to stop following-up with their doctors entirely. One woman stated, *"I had two miscarriages ... because I stopped going to see the doctor"* [C_2W_5], while the other had her stitches removed by the *sheikha* which in turn led to wound infection.

Refugees' Health Beliefs

Nearly all the women measured the quality of care they received by the effectiveness of the medication prescribed to them. Our observations revealed that what they refer to as medicines were mainly multivitamins and antiemetics (drugs that are effective against vomiting and nausea). One woman noted, *"You benefit from her [the doctor's] medication so you go to her"* [C_1W_3]. They highlighted that the doctor's role is to prescribe medication, as one woman stated, *"In Syria when a woman is sick or tired she goes to a doctor…She finishes her medicine as instructed and then she goes back to him and he gives her another"* [C_2S]. Only one woman indicated that receiving prescriptions was not as indicative of quality of care as much as the quality of communication with the healthcare provider. She stated with agitation that *"[The doctor] didn't tell me anything, she just wrote the prescription and told me to leave and God be with you"* [C_2W_2].

Digital Technologies and Current ANC Experiences, Behaviors and Beliefs

Use of Digital Technology for ANC Access

The focus groups explored current mobile communication with healthcare providers and highlighted how perceptions of healthcare providers' attitudes towards refugees influence whether the refugees contact them. Such contact with healthcare providers is initiated for a number of reasons, including: (1) to inquire about medications and prescriptions; (2) to check the availability of the doctor; (3) to ask the doctor at which clinic he/she will be available at; and (4) in emergency cases. The mode of communication through the mobile phone (phone call, text message or Whatsapp) is dependent on the message they wish to communicate and to whom they wish to communicate it. The women reported that while some doctors, mainly those in private clinics, give them their clinic phone number and/or personal mobile phone number, most PHCs do not provide them with any phone numbers.

Several women have contacted or attempted to contact healthcare providers at some point during their pregnancies. Those that described their experiences highlighted how these encounters differed according to the amount of remuneration the healthcare provider received. One woman said, *"Yes the ones in the private clinics [respond] because you pay them"* [C_1S]. Refugees perceived that the amount of payment strongly influenced the healthcare provider's responsiveness. They also highlighted that the doctors, that they had positive face-to-face engagements with, are more approachable and accessible through the phone. The women also indicated that pharmacists are responsive to communicating with them by phone. Pharmacists are viewed as an alternative to doctors for inquiries about what the women considered to be minimal health issues. Unlike doctors, who occasionally gave them their personal phone number. Women reported that they found nurses were harder to contact, because they did not share their personal phone numbers Therefore, they contact doctors that have given them their personal numbers. Additionally, one woman stated that: *"With the doctor yes [you can talk to them on the phone] but with the nurses no. You cannot talk to them at all"* [C_2W_6]; this highlights a perception that nurses are unresponsive. The majority of participants found phone calls to be the most effective and appropriate mode of communication with healthcare providers for emergencies. In non-emergency situations, some refugees would use Whatsapp or SMS to contact healthcare providers. However, others said that there is no need to communicate using mobile phones because medical issues *"can wait until we go to the clinic"* [C_4M_2].

Use of Digital Technology for Humanitarian Aid

The male participants highlighted the importance of mobile phones in accessing aid, as refugees receive text messages from UNHCR informing them of the availability of humanitarian aid including food vouchers, diesel for heating, and blankets during the winter.

Opportunities for Digital Technology to Enhance Antenatal Health

Despite our attempt to use probes to explore avenues other than those related to mobile phones, the familiarity of the women with mobile phones led to ideations centered on the use of mobiles to access ANC and antenatal health education. The women quickly suggested development of an appointment system to decrease waiting times. One *sheikha* further elaborated stating that *"they [PHCs] don't give you an appointment"* [C_3S] as the PHCs have previously refused to do so. It is important to note that this suggestion was more prominent among refugees that live in settlements a short distance away from PHCs. The idea of using mobile technology amongst themselves to organize transportation was also discussed by women but considered

to be impractical as *"we have to go on different days"* [C_3W_2]. Women residing in more isolated ITSs supported the idea of communicating with doctors using mobile technologies so as to decrease the number of times they needed to walk to clinics. One of the ideas suggested was the provision of a communication channel that would allow pregnant women to make inquiries about their medical prescriptions. This suggestion was rooted in difficulties the women were experiencing in understanding medical prescriptions given to them, *"most of them are medicine from the west [with English information pamphlets], we can barely understand the ones that have Arabic pamphlets"* [C_2W_{14}]. Another idea discussed was the creation of a platform for two-way communication with doctors. One participant commented that she *"would like to talk to the doctor and tell him my problem"* [C_3W_4]. Others said that this would be *"better than going [to the clinics]"* [C_4W_2]. Although these ideas were supported by many, some women did not think that communication through mobile technology would be as effective as personal contact with doctors. One attributed her distrust in the effectiveness of such a solution to a personal experience, "*My sister, she saw the doctor face-to-face and they gave her the wrong medicine ... What would have happened if it was through [text] messages. Really it wouldn't work with messaging*" [C_2W_4]. Others expressed similar reservations, *"When you are face-to-face with the doctor you explain your condition and they understand you, but through Whatsapp it is impossible"* [C_2S]. Overall the women did not consider mobile communications to be an adequate substitute for face-to-face interaction with doctors. Additionally, the women indicated that, based upon both their positive and negative experiences, the positive participation of healthcare providers would be a necessary success factor for any health communication platform. As one woman explained: *"It is easy to take voice notes and pictures and give results but you want the other side to actually to pull their end of the work as well"* [C_5S].

A number of the women stated that the idea of accessing health messages and education through mobile channels would be an unfamiliar experience for them. One woman said that *"we [they] did not even think of that [using mobile phones for health]"* [C_1W_9]. However, participants were responsive to the idea of receiving antenatal health education via their mobile phones. Solutions that increased access to health information were deemed acceptable, with one woman stating that she *"wishes"* [C_3W_1] that such a solution was available. The women also went a step further by suggesting that they would like to receive more personally relevant health information such as messages that are tailored to their stage of pregnancy. The women took language illiteracy into consideration and postulated that a solution that sends them health information through text messages would marginalize some women, one of which said: *"What if they send me a text message and I do not know how to read? Most of the women here are illiterate"* [C_2W_6]. Additionally, some women indicated that considerations should be made for *"someone like me that does not have a phone"* [C_1W_{10}]. In most focus groups there was a consensus that educational videos or voice recordings can be sent to one woman, the *sheikha*, and she would pass it on to the others, either through Whatsapp or by showing the video to women that do not have phones.

DISCUSSION

Previous work on the design of digital maternal health in India has mostly targeted women with only access to feature phones [2,18,19,24,33]. However, our findings indicate a high penetration of smartphones among Syrian refugees in rural Lebanon. This is consistent with the findings of Ying et al. [38] in a Syrian refugee camp in Jordan. Our findings foreground a number of considerations that need to be taken into account when designing for this population. These include: (1) aspects of distrust in medical services providers; (2) a preference expressed by the women for having the *sheikha* as a mediator of feedback and educational materials between refugees and the healthcare providers; (3) a preference for voice messages using Whatsapp over costly phone calls (as a primary method of communication); and (4) women's concerns about the use of images. These considerations highlight both barriers to and opportunities for the design of digital platforms to support ANC in this setting.

Challenges for Designing with Refugees

Our experiences of engaging the Syrian refugee population in Lebanon has resulted in a number of lessons learned to inform the configuration of future design activities. Firstly, the participants themselves identified a wide range in language and technology literacy skills amongst them, of which any design activity would need to take full account of, including prior work on designing interfaces for low literacy users [22,23]. This consideration not only has a bearing on the characteristics of any proposed digital antenatal health intervention, but also on the development of design processes and methods (such as the use of probes). The disconnect the women showed with probe-like processes and the difficulties they had in imagining how technology could be used to increase access to healthcare may be rooted in the traditional education system they have experienced in Syria. The education system is a highly competitive and structured environment which places little importance on the nurturing of creativity.

Other key considerations for design are the cultural norms regarding the acceptability of receiving and sending images. The women expressed a reluctance to send images to healthcare providers. This is in part grounded in religious beliefs (of some of the women) that images of females should not be circulated among men that are not direct relatives (e.g. husbands, sons, brothers). Another cultural consideration relates to how men should be integrated in the design processes related to their wives' health. Although the research team rescheduled visits to the ITS in order to

engage with the men more, male participation remained low. The men also hesitated to discuss ANC and family planning, an occurrence that is consistent with the Arab reproductive health literature [7]. Lack of male participation is potentially a significant barrier to the design of solutions that intend to increase access and uptake of ANC services and family planning. Finally, despite the high levels of participation, several women opted to withdraw from the study upon realization that they would not be paid to take part. Therefore, better methods for setting participants' expectations (in this respect) are required, to overcome inferences made on the basis of the presence of representatives of NGOs with the research team.

Medicalized Approach to Antenatal Care

The women exhibited a reliance on strong peer networks in seeking health advice. With the *sheikha* being the most consulted woman in the network. The women would seek her advice regarding home remedies and choice of doctors. Paradoxically, the women also emphasized the importance of consulting doctors. This points to a number of opportunities for design. Designs can either work within this dual system to support one or both elements separately (i.e. the peer network and/or doctor-refugee communication) or, designs can bridge the divide between the two, for example, to provide scaffolds by which doctors might support the *sheikha's* antenatal health knowledge and communication with her community. However, the women's strong belief in the importance of consultations with doctors and medical prescriptions, raises questions as to the extent to which the women would accept such shift in the roles of the *sheikhas* and doctors. Furthermore, any attempt to bridge communication between the formal health providers and the informal networks within ITSs is likely to face a number of organizational and political barriers, and these would be best addressed through the active involvement of NGOs and the MoPH in the design process. There has been success in linking healthcare providers to patients in Kenya, where the system allows for nurses to respond to text messages sent by women [27]. Likewise, models similar to those that use voice based technologies for health in rural India [18,33] should be explored; and extended to take account of the women's preference for the use of WhatsApp voice notes.

Opportunities for Peer Support for Antenatal Health

The culture of peer support among the Syrian refugees in the same ITS is a strength of these communities which can be further exploited. Refugee research literature has some examples of the effectiveness of utilizing peer support groups. Successful peer support models have been used to improve the perceived mental health of refugees and immigrants, and to aid them in their resettlement process [8,37]. Wollersheim et al. [37] found that sharing of experiences and information via improved mobile phone communications enhanced the psychosocial wellbeing of a group of nine Sudanese female refugees. Likewise, peer-to-peer workshops conducted among West African refugees in Australia were found to be effective in improving community knowledge regarding HIV and sexual health [8]. The importance of peer networks for information exchange among refugees has also been utilized in digital interventions that allow newly settled refuges easier access to the knowledge of their more experienced counterparts [4]. Our findings suggest for existing peer support networks among Syrian refugees to have potential to help disseminate antenatal health education and increase the outreach of current antenatal health education initiatives by NGOs.

However, our findings also revealed that when seeking to leverage peer support networks several factors need to be taken into account. In particular, the role of men within the community's social network and the hierarchal structure of ITSs. Furthermore, when scaling up peer support designs, the presence of multiple peer networks should be considered. Our findings showed that the scope to which men might be involved within female-dominated peer networks for health is limited, as they are generally not open to discussing reproductive health issues and ANC with others. However, given that our findings indicate an occasional involvement of men in the community (e.g. in transportation), there are still meaningful opportunities for engaging them (e.g. through the development of a platform where the men can organize transportation to PHCs for the women). Furthermore, the limited role that the men play in their wives' ANC further amplifies the potential of expanding the current peer support network without causing tension and role shifting within the marital relationship.

The hierarchical structure of ITSs also needs to be taken into account, in ways similar to Al Mahmud and Keyson's design of a maternal diagnostic tool for rural communities [20]. The *sheikha's* respected position in her community will very likely place her in the position to be the gatekeeper and manager of any extended peer support system. This would likely increase the women's trust and participation in the system. However, the *sheikha* is usually not the most literate or technology savvy member of her community. Therefore, consideration should be given to pairing *sheikhas* with a more literate (and/or technology savvy) women. Alternatively, capacity building activities for the sheikha can be incorporated, as has been done for health workers in rural India [19]. Scaling up of peer networks for health has the potential to expand a woman's peer network by connecting multiple spatially dislocated peer networks to each other. Similar activities have also been undertaken in under-resourced areas of rural India where women within communities have developed health educational videos for other women in the community to watch [19]. A leveraging of multiple networks has the potential to give women access to the knowledge and experience of a much larger number of women.

Opportunities for Rebalancing Power and Control in Antenatal Health

There is also great potential for digital health services to contribute to the re-balancing of power and control in antenatal health in favor of Syrian refugees. Their negative perceptions of attitude towards them have contributed to a lack of empowerment in regards of their own health. Our findings show that many women avoid formal ANC as a result of negative experiences with healthcare providers. Rushed consultations, an inability to communicate with healthcare providers, long waiting times, and the absence of an appointment system have all contributed to feelings of exclusion. A number of women emphasized their enthusiasm for using mobile phones to develop a loosely coupled integration with PHCs that would facilitate an appointment system. Such an approach would deviate from previous designs that focus on management and control by social and healthcare workers [2,18,21,24,29,33]. Likewise, in a manner similar to the use of digital storytelling to advocate for Palestinian youth [39], there is real potential for digital platforms to have a dual role in sharing the experiences of women among themselves and documenting the experiences for the purposes of health advocacy. Any such documentation would be a valuable asset in communications with NGOs and government bodies. Such a design would surface the perceived gaps in ANC services and the difficulties faced by the women.

Limitations

The challenges faced in our fieldwork led us to identify several limitations that need to be considered in future research. The first being the utilization of the *shaweesh* to access the study population. The need to pass through the community gatekeeper meant that we were not able to invite potential participants ourselves. Instead, we relied on the *shaweesh* and *sheikha* to tell the community that we were at the *shaweesh's* tent if they are interested in participating in the study. We were mindful not to exercise undue influence on potential participants, informing them (based on a script approved by the ethics boards) that they should tell potential participants that participation is voluntary and that no change in services or benefits will be associated with their participation choice. However, we were not able to ensure that this protocol was followed.

Secondly, random sampling for selection of the ITSs was not a realistic option, as registers of refugee information in ITSs are not publically accessible for privacy, political and security reasons. Consequently, we worked closely with primary healthcare and social workers to identify ITSs that reflected the variance in economic status and access to health services of women refugees. Like all qualitative work, this study provides insights to the specific communities that participated in the study.

Lastly, the fluid, and sometimes chaotic, context in which data was collected meant we sometimes experienced significant difficulties in orchestrating what were intended to be structured engagements. Focus groups were difficult to conduct, as women continued to join the sessions as they progressed. This resulted in larger groups than anticipated and made it difficult to fully engage a number of the participants. In future, such activities will need to take better account of the fluid and dynamic nature of these engagements. The fluid environment meant that not all women had an equal opportunity to talk about their phone use. Indeed, the large group sizes that resulted may also have contributed to the lack of interest in the ideation artifacts, and the women faced difficulties in attending to and envisioning the scenarios presented through the artifacts. The women tended to put the probes to one side, outside of the reach of their children who had to accompany them because no alternative carer was available.

CONCLUSION

The high penetration of smartphones and high levels of Whatsapp usage among Syrian refugees in rural Lebanon provides the HCI community with a timely opportunity to design digital platforms to improve the welfare of this community. Our exploration of the refugees' experiences in accessing ANC services however surfaced a number of factors that must be taken into consideration for design. These include: the range of literacy levels (technological and language); the hierarchal nature of social and familial structure; the roles of husbands and the *sheikha*; the women's medicalized attitudes to healthcare; and the dual formal and informal health advice systems. Furthermore, the particular importance and need to overcome the negative perceptions that the women have of the attitude of healthcare providers towards them is highlighted.

Our findings also point to a number of specific opportunities for design, from conventional infrastructure for transportation logistics and appointment making, to better communication with healthcare providers (possibly through peer networks) and digital media for health advocacy. With these factors and opportunities in mind, we conclude that there is real potential for sensitively designed digital platforms to significantly improve ANC of the Syrian refugee population living in Lebanon.

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