Identity at the Margins: Examining Refugee Experiences with Digital Identity Systems in Lebanon, Jordan, and Uganda

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ABSTRACT

This paper examines refugees’ experiences with and perspectives on the digital identity systems used by humanitarian organizations to collect, manage, and share their personal data. Through a qualitative study with 198 refugees in Lebanon, Jordan, and Uganda, we show how existing humanitarian identity systems present numerous challenges for refugees. For example, we find that refugees have little to no knowledge of the institutional systems and processes through which their personal data is managed and used. In addition, refugees are typically not able to exercise agency with regard to data that is collected about them (e.g., given choices about the data collected). At the same time, we show how refugees make active efforts to negotiate the various identities available to them, consciously weighing the benefits and constraints associated with different statuses to maximize their access to services, eligibility for employment, and spatial mobility. We use Bardzell’s lens of feminist interaction design [8] to make sense of these findings and suggest a path forward that engages refugees in the design of improved identity management systems.

KEYWORDS

HCI4D; ICTD; refugees; identity; displaced populations.

1 INTRODUCTION

Humanitarian organizations that provide services to refugees across the world are embracing increasingly sophisticated digital systems for managing the identities and personal data of the beneficiaries they serve. These digital identity management systems have the potential to provide organizations with simplified reporting, reduction in fraud, improved service delivery, and increased convenience for both organizations and refugees. However, identity and personal information are intrinsically powerful and sensitive topics and, given the vulnerable nature of the refugees being served, the complexities and risks associated with these large-scale systems are amplified. Navigating these complexities requires us to understand the experiences of the individuals that are subjected to these systems, and balance the operational benefits with an empathetic assessment of how these systems impact individuals’ privacy, dignity, and agency.

This paper contributes a qualitative study examining refugees’ experiences with, and perspectives on, the digital identity systems that humanitarian organizations use to collect, manage, and share their personal data. We conducted semi-structured interviews and focus groups with 198 refugees, in and out of camps, in Lebanon, Jordan, and Uganda in 2018. We describe the various digital identity systems that refugees encounter as they work to establish identities that grant them legal refugee status and entitlement to services (e.g., food, shelter, health services). We also uncover numerous challenges that result as individuals struggle to navigate the systems that organizations use to collect their personal information and biometric data (e.g., fingerprints and iris scan).

For example, we show how individuals have little to no knowledge or visibility into the institutional processes through which their personal data is managed and shared, including which organizations have access to their data. This lack of transparency often results in confusion, disappointment, and anxiety about the safety and privacy of their information. Despite these concerns, refugees are desperate for assistance and often have no choice but to provide organizations with all of the information that they request.

In addition, refugees are rarely offered the opportunity to exercise agency with regards to data that is collected on them (e.g., given choices about what data is collected or how it is shared). Nevertheless, many refugees make active efforts to negotiate the various
identities available to them, consciously weighing the benefits and constraints associated with different statuses (such as registered vs. unregistered) in efforts to maximize their access to services.

Moreover, despite acknowledging that they do not know the criteria that organizations use to assess their vulnerability and eligibility for assistance, we find that many refugees actively work to redefine their family structure in ways they perceive will maximize the services they receive, such as selectively registering only the woman and children. However, such actions can impact household power dynamics, since women registered as heads of households are given control over the family’s resources (e.g., food and shelter) in communities where traditionally men are the decision-makers.

We use Bardzell’s lens of feminist HCI [8] to further analyze and make sense of our findings. For example, we discuss how current identity management systems target a “universal” refugee and fail to account for different points of view or partial perspectives that may exist in different contexts. As a result, individual refugees are unable to negotiate flexibility in the nature of their identity or their eligibility for services. This further results in refugees striving to (re)define themselves in ways that better fit existing identity systems, especially if it may result in additional benefits.

We discuss how challenges with existing identity management systems impact the broader ecologies in which they are deployed, such as how difficulties obtaining and renewing identities restrict refugees’ mobility or access to basic services essential for survival. We also highlight important information and power asymmetries between refugees and the organizations tasked with advocating for them, with organizations possessing a significant amount of power over refugees, who are desperate and have no choice but to comply with any demands made of them by organizations. In light of these insights, we suggest a starting point for engaging refugees in the design of improved identity management systems, which may lead to benefits for both humanitarian organizations and refugees.

2 RELATED WORK

The concept of identity and its importance in the social, cultural, and historical lives of humans has been discussed at length in psychology and the social sciences (e.g., [29, 31, 34, 53, 54]), and has been shown to have direct relationships to social, cultural, and historical contexts [9]. Theoretically, ‘identity’ refers to social category, defined by membership rules and socially distinguishable features that a person takes a special pride in, or views as unchangeable but socially consequential [20]. The theoretical concept of identity has also been critiqued for being ‘asked to do too much’ [12] and as a result may have limited analytic utility. Brubaker and Cooper [12] argue for more specificity and application of the concept, while Whitley et al. [54] argue for greater attention to the interplay between the distinct phenomena of information systems, identification, and identity. In our work, we focus on the identification of individuals as refugees by humanitarian organizations and institutions, whilst being sensitive to the broader concept of identity as a theoretical social category.

Given the strong influence identity has in defining social and cultural milieus, it becomes especially crucial to study identity in the context of refugees and displaced populations. Although there have been abstract mentions in the literature of the linkage between identity and refugees [37, 38], there is little literature available that discusses the changing nature of refugee identities in the digital age. With the global proliferation of digital technologies, digital identity is now fundamental in defining a refugee’s status, especially in camps. Although prior research has explored digital identity in general (e.g., [3, 30, 33]), very few empirical studies specifically focus on digital identities in the context of refugees.

Our research also contributes to a growing body of work examining the role of the computing community in responding to refugee crises [2, 41, 43, 52]. For example, shelter dynamics is an important topic that is closely related to our work on identity and registration systems, since shelters are often assigned using information provided to these systems. Sabie et al. [35] used ethnographic methods in Syrian and Iraqi camps to explore cultural and social dynamics around shelter. Building on this, Nabil et al. [32] did fieldwork in Jordan that shows how decorating shelters provides an escape from the camp and compensates for loss of identity, home, and leisure.

Connection and community-building within refugee communities has also received recent attention in the literature. For example, Almohamed and Vyas [4] use ethnographic research to identify themes around social isolation, cultural backdrops, and the role of technology in the lives of refugees and asylum seekers. Aal et al. expose challenges with physical and social infrastructure through analyzing a refugee camp computer club [1], while Schmitt et al. examined community-level physical access divides in camps [36]. Xu et al. conducted a study to promote participatory community building via mapping technologies [58], and further discussed data-driven community development in follow-up work [57].

Other research highlights vulnerabilities associated with resettlement [5] and the role of digital technologies in helping refugees to integrate into new environments and attain independence [7, 26]. In addition, work has examined the security threats and vulnerabilities associated with refugees in the digital tech space [13, 16], a topic that our work touches on as well. A variety of strategies have also been used to help refugees rebuild social capital and a sense of community in displaced environments [6], including community radio [27], co-located social media platforms to help refugees find their voices [55], human-in-the-loop messaging to reduce language barriers [11], leveraging social ties to bridge the social and economic divide by forming computer clubs in Palestinian camps [61], and utilizing the importance of food in camps to develop social capital [21]. This research is orthogonal to our work, which focuses more on how refugees interact with organizations and the digital systems that organizations use to make refugees legible to the organization.

Another set of papers have worked to understand refugees’ access to or usage of health services in camps. Talhoub et al. [42] used focus groups to identify contextual and cultural factors that can inform the design of digital technologies to support refugee antenatal care. Carrying this forward, they then explored the concept of refugee-led community radio shows to deliver health information and discussed community dynamics in utilizing technology for health [40]. Focusing more directly on technology access and use, research has explored refugees’ use of the Internet and mobile communication devices, both in adult populations [56] and with youth [60]. Yafi et al. studied how Syrian youth at the Za’atari Camp in Jordan use information and mobile technologies in their daily
lives [59]. Fisher et al. conducted participatory design workshops at a Syrian refugee camp in Jordan to learn how youth help others to use technology [22]. Boulus-Rødje et al. worked with children in Palestinian refugee camps and explored issues around digital fabrication in developmental and educational settings [39].

Our research contributes to this literature with the first study of refugees experiences with, and perspectives on, the digital systems that humanitarian service providers use to render people legible to their organizations. We highlight numerous challenges that refugees navigate as they struggle to maximize the services that they are entitled to, discussing how information and power asymmetries negatively impact refugees’ ability to exercise agency and control over their personal information and identities.

3 RESEARCH METHODS

Research Sites: We conducted our IRB-approved study with 198 refugees in Lebanon, Jordan and Uganda, in and out of camps, in 2018. We chose Lebanon and Jordan because they have absorbed one of the refugee movements as people have fled Syria, yet offer differences in terms of identity systems in use. As of December 2017, Lebanon had 1,018,057 registered refugees and asylum-seekers, predominantly in the Bekaa Valley but also in urban and peri-urban areas around Beirut [47]. We spoke with refugees in the Bekaa Valley and in central and peri-urban Beirut. Lebanon is distinct because most refugees are in informal tented settlements, and the registration and data management systems have reflected this.

In 2018 Jordan had the second highest share of refugees compared to its population in the world, 89 refugees per 1,000 inhabitants [46]. Although the majority of Syrian refugees in Jordan live in urban areas, 126,490 refugees live in camps, with Zaatari and Azraq, the two largest, hosting 78,554 and 41,089 respectively [50]. We spoke with refugees in both these camps and in the capital, Amman, in February 2018. Jordan is distinct for its highly developed camps and the use of advanced biometric technologies.

As of February 2018 there were 1,444,873 refugees and asylum seekers in Uganda, with 21% in Yumbe, the location of Bidi Bidi camp [51]. We spoke with refugees in Bidi Bidi in March 2018. Uganda is distinct because the government, through its Office of the Prime Minister (OPM) [44], has taken the lead in registering and managing refugee data. It also has one of the most progressive policies towards refugees, granting them legal recognition and giving each refugee household ownership of a small parcel of land.

Recruitment: Participants were recruited through a combination of invitation by partner organizations, personal networks, and snowball sampling [23]. Save the Children, an international NGO, provided logistical and initial recruitment support, inviting beneficiaries to participate. We also drew on our research assistants’ personal networks to access community-based organizations active in supporting refugees. At all sites we used snowball sampling, [23] asking participants to introduce us to people they knew.

Qualitative Methods: We used a combination of semi-structured interviews and focus groups to engage with participants (see Table 1). Our question guides were structured around topics identified in the literature, stakeholder interviews, and pilot research. We sought an understanding of: refugees’ experiences using identity credentials before displacement; their first experience of registration and using new identity credentials; using refugee credentials to obtain services; everyday experiences of proving who you are; and managing different identity credentials. We also probed participants’ understanding of how organizations manage their data, and the barriers and workarounds used to maximize access to services.

Interviews and focus groups took place in a mix of locations, including NGO offices in camps, homes, food distribution points, and shops. We began by explaining the purpose of our research and obtaining the participant’s consent. Sessions lasted approximately one hour and were conducted in the participant’s choice of English or Arabic. The majority of participants in Lebanon and Jordan (approx. 80%) chose Arabic, while participants in Uganda were more evenly split between both English and Arabic. Sessions were audio recorded with permission from participants. In a few cases, participants declined to be audio recorded and so instead we took detailed handwritten notes. Participants were not compensated.

Participants: Table 1 provides some demographic information about our participants at each research site. In total, we spoke with 198 refugees: 86 men and 112 women. Almost all of our participants had access to a mobile phone, either owning their own device or sharing a device with family members and/or friends. The most common applications that participants reported using were Facebook and WhatsApp, which participants ubiquitously described using to keep in contact with family members or friends, both in the host country and in other countries (e.g., back in their home countries). In addition, mobile money applications were commonly mentioned as being useful for sending and receiving money.

Data Analysis: Audio recordings were professionally translated into English (if necessary) and transcribed. We then analyzed the transcripts and our copious field notes thematically [10], beginning with a comprehensive reading of the transcripts during which we identified initial codes. We performed multiple passes over the data to iteratively refine codes and ensure they accurately represented the data. Coding was performed by two research assistants with input, supervision, and discussion with the broader group after each iteration. Our final set of 57 codes were formalized in a codebook and obtaining the participant’s consent. Sessions lasted approximately one hour and were conducted in the participant’s choice of English or Arabic. The majority of participants in Lebanon and Jordan (approx. 80%) chose Arabic, while participants in Uganda were more evenly split between both English and Arabic. Sessions were audio recorded with permission from participants. In a few cases, participants declined to be audio recorded and so instead we took detailed handwritten notes. Participants were not compensated.

Table 1: Summary of participants and research methods

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We emphasize that the nature of our data is qualitative, not quantitative, so we do not report on raw numbers of participants who made certain statements in our data and analysis.

4 ESTABLISHING DIFFERENT IDENTITIES

When individuals flee their own country and enter that of a host government, they also enter a network of organizations and systems that are part of the humanitarian response. The organizations and systems that make up the humanitarian response label and classify people in order to make them eligible to the systems employed by organizations to manage the provision of services. The labels and classifications are used to organize and ration the provision of scarce resources, according to diverse and complex criteria. Some categories, such as specific nationalities, genders or ages are categorized as priorities for the provision of services, and different organizations have different priorities. For example, UNHCR, the UN’s Refugee Agency, serves all refugees and has a legal mandate to recognize refugee status. By contrast, UNICEF, the United Nations Children’s Fund, prioritizes young people, while the priorities of many non-governmental organizations (NGOs) are set by donors.

As organizations interact with individual refugees, they create records and issue credentials in order to identify and authenticate that people are who they say they are. Through the journey of interacting with these diverse organizations and services, individual refugees collect many different identity credentials, from the UNHCR registration document that identifies them as a recognized refugee to temporary project-related credentials issued by NGOs. Refugees frequently end up being identified by multiple organizations, possessing and managing multiple identity credentials, with different identities holding different functions and levels of importance in the refugees’ lives. Common to many of these systems which record an individual’s data is that they are increasingly digital, with biometric and biographical data recorded in computerized systems. We describe refugees’ different identity credentials and the processes for obtaining them before discussing the challenges refugees face managing these credentials.

4.1 Registration with UNHCR

Our findings show that the most important identity credential for most refugees is a UNHCR identity document, which typically consists of a physical ID card or piece of paper with a barcode. This credential is obtained through official registration with UNHCR and provides legal recognition of refugee status. It is a material symbol of the refugee’s legal status and entitlement to benefits, and is critically important for establishing identity and accessing services from multiple organizations. For example, the World Food Program and other NGOs that provide services on behalf of UNHCR, distribute assistance to refugees based on their registration status with UNHCR. As such, a person’s ability to obtain food, shelter, health, and other essential services is strongly tied to their UNHCR registration card. As one participant said,

“The [UNHCR] card is the very important one. At the distribution centers it’s what they use to give you a ration card. Secondly, when you go to the hospital, and thirdly it shows that you are a refugee.” (Focus group, Uganda, Woman)

As this quote suggests, the UNHCR registration card is also important because it confirms the refugee’s right to be in the host country, which is particularly important in countries, such as Lebanon and Jordan, that limit refugees mobility, access to employment, or state services. Many participants said that their UN registration document was very important to carry with them and how it was often inspected by security forces who stop refugees and demand they prove their status and identity. One participant said,

“In Syria we never had to carry any documents with us. Right now, in Lebanon, the situation is very different. Having to carry IDs at all times causes stress because if the military catches us without IDs, we could be in trouble.” (P8, Lebanon, Woman).

Interestingly, our analysis revealed that this legal status can impact men and women differently, with women often possessing greater mobility than men because security forces stop and interrogate men more than women. One participant explained,

“When the military come to the house, they don’t talk to women, only men.” (Focus group, Lebanon, Man)

We learned from our participants that registration with UNHCR takes place in dedicated centers equipped with private interview spaces and biometric scanning equipment. Each refugee participates in an in-person interview that can take up to a few hours. If the refugee has a family, the whole family is registered as a single unit, with one adult designated as head of the household. During registration, participants said that they were asked many personal questions about life in their home country, reasons for becoming a refugee, experiences getting to the camp, etc. A participant said,

“[The UNHCR] asks about the experience you had, how you were in Syria, what you used to do, and what is the reason that made you leave to here for refuge, and these things. We gave them a summary, how we arrived, and how we arrived to them.” (Focus group, Jordan, Man)

Many of these questions aim to enable the UNHCR and other aid organizations to perform vulnerability assessments, in which refugees who are deemed to be more vulnerable or high-risk may receive additional assistance. These vulnerability assessments are based on complex criteria that are largely opaque to refugees, who are often nervous about the interview because they fear making mistakes and failing to get access to much needed services, a challenge we discuss in detail in Section 5.3. The data collected about the family is usually stored in proGres [49], the identity management software used by the UNHCR.

In addition to collecting the refugee’s biographical information, the UN representative also records their biometric data, including fingerprints, iris scans, and facial images, which are typically stored in the UNHCR’s Biometric Identity Management System (BIMS) [45], which integrates with proGres. In Jordan, biometric data was collected by Irisguard, a private biometrics company that provides their technology to the humanitarian sector.

When we asked participants for their opinions regarding biometric data collection, we discovered that most refugees view the process positively since it allows organizations to control the distribution of services and curb fraud. A participant in Jordan said,
“My personal take on the procedure is very positive, because there are thousands and thousands of refugees here, so you need a solid identification system to identify them all accurately. So in terms of documenting the identities in the computer system, the eye scan is the most reliable … simply because it is the one thing that you cannot forge. Any documents can be forged, the eye scan no.” (P34, Jordan, Woman)

Although we found that participants generally viewed the linking of services like food distribution to people’s biometric data as a positive step, biometric verification was not able to solve all of the fraud or corruption issues that our participants described. For example, our data revealed how refugees believe some people who are responsible for distributing food to communities steal a portion of the food for themselves. One participant said,

“The ones who offload [the food trucks]. They are just taking [it] and we are left with little food … now that’s a big problem … they take two kilos from each person’s 12 kilograms [of food].” (P100, Uganda, Woman)

Finally, although the vast majority of our participants viewed biometric data collection as a positive step, a small number did express concerns about the biometric systems. These concerns most often stemmed from rumours and perceptions rather than issues like data sensitivity. For example, one participant said,

“I heard stories that the eye scanner might steal my eyes, is that true? Many people are afraid of it.” (P170, Uganda, Woman)

4.2 Registration with other organizations

In addition to UNHCR, people also register with a wide range of other organizations in an effort to access desperately needed services. These services are often refugees only source of support, particularly in countries refugees have limited access to labor markets or state welfare services. One participant said,

“Only people who are here illegally don’t approach any NGOs for services, they live a very rough life in makeshift shelters, cold weather, no food or supplies.” (Focus group, Lebanon, Man)

Some participants described how they registered with any organization that they came across, sometimes losing track of all the organizations that they registered with. One participant explained,

“For me, I registered in so many organizations that I do not even remember any of their names. Whenever we found or heard of an organization we went and registered every time.” (P184, Lebanon, Woman)

Although registering with multiple organizations required people to provide the same information over and over again, they said they did not mind the repetition if it led to assistance. One said,

“We don’t get tired [when they ask the same questions over and over] because all we want is to get help. If help can come, no problem.” (Focus group, Uganda, Woman)

However, our analysis showed that registering with so many organizations led to confusion and frustration among the refugees. In many cases, refugees were unable to associate specific services received with the organization responsible. They also frequently confused different organizations and did not understand how the organizations made decisions about who to help. A participant said,

“I registered with a Danish organization and received nothing, not even bed blankets. I registered and went through a whole process and when I thought I was finally getting something, they informed me that I did not make the grantee list.” (P59, Lebanon, Woman)

As this quote suggests, refugees often lack knowledge or awareness of the assessment criteria used by organizations to apportion scarce resources, leading to disappointment and frustration when organizations who recorded their information failed to deliver any benefits. Nevertheless, many participants still registered with any organization that might offer assistance. One participant said,

“At the beginning other NGOs showed up and registered refugees with the promise of assistance. Most of them didn’t deliver on promises. Refugees lost trust in them and they have suspicions of corruption in the humanitarian system, where they think NGOs take [refugee] names for their numbers and funding but don’t deliver to refugees. However, they still register with anyone who offers help, like a drowning person hanging to a straw in the ocean.” (Focus group, Lebanon, Man)

5 CHALLENGES MANAGING IDENTITIES

Having described the different types of identities that refugees create as they try to obtain assistance from humanitarian organizations, we now discuss additional challenges that our analysis surfaced as refugees work to establish and manage these credentials.

5.1 Registration is time-consuming & laborious

A big issue for participants was that the process of registering with organizations was time-consuming and laborious. Many participants described that it could take months or even years to register with the UNHCR, with delays arising due to a variety of reasons. For example, in Lebanon and Jordan, obtaining refugee status was complicated by the host government’s restrictions around the formal registration of new refugees, and the waiting time before refugees could register ranged from months to years. This can result, as it does in Lebanon, in what UNHCR terms ‘de-facto’ refugees—people who are not legally recognized as refugees but who UNHCR serves as though they were, providing the same services and support.

To overcome the long waiting times before registering, some participants described how they used connections at the UN to manipulate the waiting times for appointments. One told us,

“I would go to the UN, I made an appointment. Of course they gave me one in nine months, and honestly, I pulled some strings and I made the appointment earlier. I know someone who works [at the UN], and he made it sooner … It was in September, he rescheduled it to April. Five months early.” (P182, Lebanon, Man)

In Uganda, participants described the difficulties of waiting outside in long lines for days trying to register. A participant said,

“We would stay from morning to sunset waiting to be registered, even the children suffered from the sun. There was no water to drink. People were suffering … some
people were insulting us. They said that we Sudanese were dirty.” (P45, Uganda, Woman)

As this quote suggests, many refugees reported that they were often shouted at or humiliated by people who lived in the host country. However, in these situations, they felt that they had no choice but to endure the humiliation since they badly needed the assistance that was being provided. One participant said,

“You just obey because you are from a foreign land. You humble yourself because you need the food.” (P69, Uganda, Male)

Even after refugees reached the front of the line and began the registration process, obtaining an identity card often took multiple days, in part because of the overwhelming number of people who needed to be registered. A participant described,

“The process was very laborious and long. You could not just walk into the interview room. The numbers of people were overwhelming. It took a minimum of three days. They interview you today, take your photo the next day... And on the third day, you go and pick up your card.” (P58, Uganda, Woman)

5.2 Renewing or changing data is difficult

Our participants also faced challenges changing or renewing their information. In Lebanon and Jordan, the UNHCR requires all refugees to renew their registration periodically, but many participants said that it was difficult or impossible to do so. One participant said,

“For us, it is the renewal issue that is a nightmare... and it is stressing us all. We need to renew the UN papers [every] one or two years, and in many cases we are not able to do that.” (P164, Lebanon, Woman)

Once again, participants described how they were only able to obtain an appointment with the UNHCR to renew their registration months or years in the future. Being unable to renew registration documents caused significant problems for our participants, especially men, who may be stopped by security forces and found to have expired papers. One participant described being taken away and interrogated by police for several days. He told us,

“[The policeman] looked at me and said your card has expired. I said I knew it was, but I was working on renewing it. They told me to get in the car. I got in with them and they took me for three days to the intelligence agency.” (Focus group participant, Lebanon, Man)

Our participants also discussed how UN and other organization workers were in a position of power over refugees, which made the refugees afraid to follow-up too frequently on the status of their case since, if they annoyed the UN workers, they could use their power to discriminate against or make the refugees’ lives more difficult. One participant told us,

“Maybe if I bother [the UN officer] with many visits and annoy him, he can just strike out my name.” (P124, Jordan, Man)

In addition to difficulties renewing UNHCR identity documents, our participants described how changes in personal status, such as getting married, created challenges because updating their registration is difficult and takes a long time. One said,

“Transferring something from one file to the next is a hassle. Like marriage. I am in my parents file. I want to marry a girl who is in her parents file. For us to have our own file, it is very hard. Tomorrow...try calling the UN. Ask them to give you an appointment and say you want to review or edit my file... they will say it would take a year.” (P82, Lebanon, Man)

Similarly, trying to record the birth of a new child requires refugees to navigate many different bureaucratic systems to register the birth before being able to try and add the child’s information to their UNHCR file. As one participant described,

“Newborns have to be added to the [family’s] UNHCR file. A birth certificate is issued from hospital. This paper is certified from mukhtar [town chief] who gives them the new official birth certificate. Then they go to the municipality to get it certified and registered in the system. Then they take that to UNHCR to add children to their file. It’s very difficult to communicate with UNHCR.” (Focus group participant, Lebanon, Man)

5.3 Identity systems lack transparency

Another major challenge that our analysis surfaced is how, from the refugees’ perspectives, existing identity systems suffer from a severe lack of transparency, including when their data is collected, updated, used, and shared. Many participants explained that, when asking detailed and intrusive personal questions during registration processes, representatives from various organizations (including the UNHCR) often did not explain why they needed all this information or how it would be used, despite humanitarian organizations commitment to ‘informed consent’ [25]. One reason for this lack of explanation was due to workers at registration centers being overwhelmed by the number of refugees. As one participant said,

“They did not explain [why they need this information]. They were also asking under pressure because the population was too big. That did not give us time to ask.” (P46, Uganda, Man)

Despite not understanding why their personal data was being collected, how it would be used, or how it would result in services that help them, our participants explained that they really did not have any choice but to provide the information that organizations requested from them. One participant described,

“You as a refugee, any information...that is going to take place, you cannot say that you don't want to. You just humble yourself and do it. If you don’t want to, that means that you are bringing suffering upon yourself.” (P31, Uganda, Man)

In addition to being required to provide all information requested from them without understanding how it would be used, our participants discussed how the flow of information occurs in only one direction: they provide information to organizations but are unable to get information back from organizations. Many participants said their attempts to contact organizations after registering with them were unsuccessful. For example, a participant in Lebanon who was having difficulty registering her daughter in school due to lack of documentation said she was told to call the UNHCR “hotline”,

“Transferring something from one file to the next is a hassle. Like marriage. I am in my parents file. I want to marry a girl who is in her parents file. For us to have our own file, it is very hard. Tomorrow...try calling the UN. Ask them to give you an appointment and say you want to review or edit my file... they will say it would take a year.” (P82, Lebanon, Man)
but this line was never answered. Other participants faced similar challenges trying to renew their UNHCR registration. One said, “I went to renew [my registration] and they gave me a number to call. I called the number, and they said your card is not eligible.” (P47, Lebanon, Man)

In the absence of official explanations for why organizations need certain pieces of information, refugees often came up with their own explanations. For example, although a refugee’s biometric data is primarily collected to verify their identity when receiving services, one participant perceived this data would be used to determine her ethnicity and therefore her eligibility for refugee status. She said, “They did [the biometric scans] because they wanted to confirm if I was a Ugandan or Sudanese. I was scared about the whole process.” (P121, Uganda, Woman)

Participants were also acutely aware that the information they provided was somehow linked to vulnerability assessments that organizations perform to determine who is eligible for assistance. The lack of transparency into how these vulnerability assessments are calculated meant that our participants usually did not understand an organization’s criteria for distributing aid and, in many cases, believed that the process was unfair. One participant said, “We see [other] families with same aged children. Some of them even have cars and still they receive food aid. My brother has four young children, he receives nothing from the UN.” (P185, Lebanon, Woman)

Several participants also perceived that only those who had “wasta” or connections seemed to receive certain benefits or favors. For example, one participant described how it was impossible to find employment unless you knew the right people, telling us, “In short, it is only the people that have wasta … they get work and that is that.” (P120, Jordan, Man)

Without official explanations of how vulnerability assessments are calculated meant that our participants usually did not understand an organization’s criteria for distributing aid and then took steps to try and maximize their chances of receiving services. For example, many participants perceived that if a man registered as part of the household, the family would be denied aid. One participant said, “During this time, the UN has been denying a lot of people the assistance they are providing. There are some people who see it that if there is a man, that they won’t get assistance.” (P182, Lebanon, Man)

As a result of this perception, we heard numerous stories of how men would choose to not register with UNHCR. Instead, the woman and children would register, with the woman listed as the head of the household. As one NGO employee said, “We met a lot of men whose wife and children are registered, and [he] did not register . . . the men with family, they don’t want to register, but they register their family.” (NGO employee, Lebanon, Woman)

Registering the woman as the head of the household gave her control over the assistance that the family received, such as food, shelter, and, in Uganda, ownership of the plot of land granted to each refugee household. However, this new dynamic of female-headed households also led to a range of unforeseen consequences, particularly since all our participants are from relatively patriarchal societies in which men are typically the decision-makers and control the family life. For example, one participant in Uganda, who also worked with an NGO that provided support to families and survivors of domestic violence, described how the women being the head of household issue is a big cause of domestic violence. Men want their position and control back, and may abuse women to get it. Further, we observed additional gender dynamics that arose when organizations, including UNHCR, assigned community leadership roles to legally-registered women. One man said, “The UN . . . assigned a woman as the head of this neighborhood. So how are we expected to talk and deal with her . . . it bothers me. It’s hard for me accept issues related to my life decided by not only a woman, but also a strange woman to me.” (P124, Jordan, Man)

### 5.4 Data privacy and information sharing

We turn now to our participants feelings towards the privacy of their personal data and how it might be shared across organizations. Personal data privacy is particularly important for refugees, who have often fled persecution and fear being targeted if identified. In addition, the increasingly digital nature of identification systems means it is easier for organizations to share data than ever before.

As discussed in Section 4.2, many participants gave their personal information to any organization that might provide assistance. However, our analysis shows that the data sharing practices of organizations is opaque and most participants had no idea if or how organizations might share their personal information with other organizations. As one participant in Jordan put it, “we never asked and we really do not know.”

When asked how much they cared if organizations shared their data with others, we received a range of answers. Some participants viewed data sharing among organizations as a positive and said that they did not mind if UNHCR shared their information since it might lead to additional opportunities for employment or assistance. Other participants said that they did not care about organizations sharing men’s data, but did not think it was appropriate to share women’s personal information. As one participant said, “I would kill them if they share the women’s photos and information. This demeans the women more than the men.” (P124, Jordan, Man)

Some participants were so concerned about the potential consequences of data sharing that they avoided registering altogether. For example, a Syrian refugee living with his family in a one-room apartment in Lebanon told us, “Everybody was registering with the UN, but we did not. We were suspicious and scared. We don’t know if the UN shares information with anyone, so that is why I did not share many things with them.” (Focus group participant, Lebanon, Man)

Many participants felt that some of the information they provided was safe for organizations to share (e.g., their names or family size) but were concerned that sharing other kinds of information that they had been required to provide might lead to future political persecution or immigration problems. One participant told us,
“The most important question [UNHCR] asked is: what area in Syria are you from, what is your political ideology, have you been a part of protests? ... the problem is when they share the questions with the embassies for resettlement, they go back to the initial file. For example, if someone has participated in organizing protests or revolts, this affects his [immigration] case with some countries.” (P82, Lebanon, Man)

Our participants’ fear of political persecution extended beyond their concerns regarding information sharing among organizations and impacted their own sharing practices on social media. But, in contrast to the lack of knowledge or ability to manage and control the personal data held by humanitarian organizations, participants described how they actively manage personal privacy on social media. Some discussed how they avoided revealing political information, for example, by refraining from engaging in conversations online that touched on the topic of politics. A participant said,

“Mostly when I am chatting [on Facebook], I ask [my friends] what is happening in their life, when can we meet again, future plans … For me the topic I don’t talk about is politics. Because it is what caused us problems that made us refugees. I have fear of it. Sometimes I feel like if I engage in such talk, someone may just come and attack me.” (P71, Uganda, Man)

Other participants described how they, and other refugees they knew, went even further by using fake names on any email accounts or social media profiles in an effort to hide their identities from the authorities. One participant told us,

“My email is a pseudonym. My profile is a pseudonym. There is no real name … Because they will apprehend me, catch or arrest me immediately for anything. Most people [use fake names].” (P147, Lebanon, Man)

Yet another participant believed that it did not matter if people hid their names or not, the government would be able to know about anything that the participant posted online, telling us,

“With Facebook there is no privacy. When you have your photos, whether you are hiding or not for security reasons, already they know.” (P71, Uganda, Man)

In addition to concerns about online surveillance and tracking of social media activity by authorities, participants worried about physical inspection of their devices by security forces and described how they tried to manage these risks. One participant in Lebanon explained how he had been stopped, interrogated, and beaten at security checkpoints. During these interrogations, he was glad he had left the smartphone he used behind, a conscious decision to prevent the police going through his phone, either identifying his contacts or using the content to further detain or harass him.

6 DISCUSSION

Our analysis shows how the current state of humanitarian identity systems presents many challenges for refugees. We now use Bardzell’s feminist HCI framework [8] of six design qualities (pluralism, ecology, embodiment, self-disclosure, advocacy, and participation) to make sense of these challenges and suggest a starting point for the design of improved identity management systems.

6.1 Pluralism

The quality of pluralism refers to “design artifacts that resist any single, totalizing, or universal point of view” [8]. Our analysis suggests that the digital systems used by humanitarian organizations to manage beneficiary data have been designed for a typical (i.e., “universal”) refugee rather than to support diverse or partial perspectives of different refugees in different contexts [24]. Indeed, although our research took place with diverse communities in multiple countries, many of the digital systems in use were the same UNHCR systems despite contextual and cultural differences.

UNHCR’s ProGres is designed to be a universal registration system, intended for use in the diverse contexts in which the organization operates. There is evidence that the same universal, totalising design leads to common experiences and outcomes for refugees beyond the three countries our research focused on [28]. Latonero et al.’s 2019 study of refugee experiences in Italy, including interactions with UNHCR’s ProGres, found “The systems that use identity data to classify individuals along political and economic lines can have lasting effects on their rights and freedoms.” They also found common experiences in relation to informed consent and agency, noting that “Migrants exchange identity data for resources without meaningful consent” [28]. More broadly, there are efforts to standardize the digital management of refugee support, with organizations such as the UN’s World Food Programme seeking to integrate all its support through their beneficiary management platform SCOPE [14], and aid providers such as the UK’s Department for International Development funding research into universal standards for refugee registration [17]. The commonality of Latonero et al.’s findings and the trend towards system standardization points towards possible generalizability of our broader findings, although further research is needed to confirm this conclusion.

However, although this universal approach to rendering refugees legible to organizations has many benefits for the organizations (such as simplified reporting, training, and system maintenance), we see that it leads to challenges for individual refugees who are constrained within the institutional bounds of these systems. For example, many refugees have no choice as to what identities or registration cards they are eligible for, or the categories and labels that organizations assign to them. Further, whilst these categories, such as refugee status or specific vulnerability criteria that determine access to specific services, are based on assessments of refugee needs, individual refugees are unable to negotiate flexibility in the nature of the identity or in their identification and eligibility.

In contrast to the systems used to register and manage service delivery, we show how the social media platforms that refugees use to share information do a better job of supporting pluralism and different points of view. Although social media platforms such as Facebook and Twitter have well-described limitations and constraints around privacy and flexibility over data sharing and identity construction (e.g., [18, 19]), they offer far greater means of individual end-user agency and control over personal data. Many refugees exercised individual control in the use of these systems, for example using fake names, being careful about revealing information online (not least political affiliation or views), or using different phones in specific contexts (i.e., not taking their phone from Lebanon to Syria). This shows that individual refugees have the capacity and desire to
exercise control and manage digital platforms, which would apply to institutional systems as much as it does to social media platforms. In other words, when individuals are able to express different points of view and exercise control over personal data, they do.

### 6.2 Ecology

The quality of ecology integrates an awareness of design artifacts’ effects in their broadest contexts of use, as well as an awareness of how design artifacts affect all stakeholders [8]. It invites us to attend to the ways that design artifacts reflexively design us. This quality manifests in our data in several ways.

For example, UNHCR’s registration system includes the designation of a ‘head of household’, the person that is issued food rations and, in the case of Uganda, granted ownership of the government-issued plot of land. This designation is part of UNHCR’s registration system, which works the same in Lebanon, Jordan, and Uganda as it would anywhere else. The head of household is typically the oldest family member. The universalism of this sociotechnical system has diverse effects. It structures the family relationship so that it is legible to a system that then confers rights and privileges—either confirming the man as the head of the household or, in some cases, restructuring the family unit. This restructuring of family life by registration systems can take different forms. For example in Uganda, because women often fled before male relatives, they were registered as heads of households, making them the official recipients of UNHCR rations and Ugandan government land. Many women described how this granted them a greater degree of agency and control over their family life. It also meant they took the place formerly occupied by their husbands or male family members, which sometimes caused problems when the men subsequently arrived and sought to reclaim their position of power and authority.

Another example of ecology can be found in the power asymmetries between refugees and those responsible for providing services to them. Specifically, we show how refugees lack of power and desperation for services make them vulnerable to exploitation. For example, in Uganda, refugees were forced to hand over a portion of their food ration to the people who delivered the food to their homes. These examples illustrate the diverse relationships between sociotechnical systems and their broader contexts of use, as well as how social life and relationships interact with technology, with both positive and negative outcomes.

### 6.3 Embodiment

The quality of embodiment urges “focalizing the agency of interaction not on the interface or its designer, but the bodies, motivating drives, and primordial urges of users” [8]. In our research, we see many ways in which the identity management systems that determine refugees’ legal status and eligibility for services have far-reaching consequences for refugees’ “bodies, motivating drives, and primordial urges.” For example, refugees’ legal recognition through registration with UNHCR was often instrumental in gaining access to basic, tangible services that were essential for survival, including shelter, food, and health services. In addition, challenges renewing refugee status sometimes led to mobility problems for refugees, especially men. We heard stories from participants of how they would be stopped and interrogated by security forces, and detained or beaten up if they did not possess valid identification.

Given the high stakes for refugees when it comes to how the data they provide to organizations does or does not result in tangible benefits necessary for survival, it is unsurprising that they strive to actively negotiate the identities available to them (despite limited opportunities to do so), consciously weighing the benefits and constraints associated with different statuses in order to access services, ensure eligibility for employment, and preserve spatial mobility. For example, many refugees have partial, or perceived, knowledge of organizations’ registration processes, which leads them to adopt different strategies in negotiating these processes—including avoiding registration completely in some cases or selectively registering members of households because they perceive that female-headed households receive more benefits than male-headed households. In addition, many refugees we spoke with voiced concerns about registration interview questions, such as place of origin, and anxiety about the consequences of this data being shared (e.g., on future immigration opportunities or safety from political persecution).

### 6.4 Self-disclosure

The quality of self-disclosure refers to the extent to which software renders visible the ways it effects users as subjects [8]. It calls users’ awareness to what the software is trying to make of them and creates opportunities for users to (re)define themselves to become the kind of user the software is for, or set aside the parts of themselves that are less relevant to the software. In other words, the software gives users an identity they are pressured into accepting.

The quality of self-disclosure on the part of humanitarian registration systems is particularly important in our context. Indeed, the very process of registration and the establishment of eligibility to specific services rests on institutionally defined categories into which individual refugees must conform. At the same time, refugees and other displaced persons are by definition extremely vulnerable. They are desperate for assistance and, as our data shows, many will strive to define themselves in ways that make them legible to these systems if there is even a chance that it will lead to additional services. In these contexts, the organizations collecting the data hold all of the power, which also highlights challenges obtaining true consent to collect and share people’s personal data [25].

The lack of self-disclosure of these systems is also apparent in individuals’ lack of understanding of how organizations make decisions about their eligibility for services, in ways that echo other types of systems where black-box processes, such as algorithms, determine important outcomes. The experience of people who have little to no understanding of how organizations assess their vulnerability or needs is similar to the increasing number of ways in which unknown algorithms determine the choices and options available to individuals all over the world, from credit scores and search results to online prices and news information. Transparency of these vital decision-making processes could enable broader understanding of how organizations distribute scarce resources, yet such self-disclosure might also invite efforts to game the system. At the heart of this debate is of course the nature of the relationship between institutions and individuals, and who gets to decide whether trust and transparency can co-exist.
6.5 Advocacy

The quality of advocacy focuses on ensuring technology is progressive and attempts to bring about political emancipation [8]. Although the UNHCR and other organizations in our research ostensibly exist to advocate for refugees and improve their quality of life, these organizations are also focused on and working within the status quo, and must conform to the political, social, and cultural environments of the countries in which they operate. For example, we saw how, when host governments say that no more refugees are allowed to be registered, the UNHCR must follow their decision, even if it negatively impacts refugees. As such, organizations need to pay attention to the ways in which they may perpetuate regressive and harmful practices and structures [8].

Another way that the quality of advocacy manifests in our work is in how refugees who were desperate for services chose to share sensitive personal information with organizations despite skepticism that those organizations would deliver the services promised. In these examples, participants described how they worried that the very organizations supposed to advocate for them instead used their data in ways that only benefited the organization (i.e., to obtain funding) but did not provide benefits to refugees.

We also see many examples of how, when organizations’ practices and policies clash with refugees’ needs and opinions, the organizations have all the power, with refugees often forced to conform to organizations’ requirements. For example, in most cases, refugees have no choice but to share their data if they want access to services. They are also required to provide all the information requested, with no choices for holding some information back or asking that certain pieces of information not be shared with other organizations.

Many systems also currently prevent refugees from being able to advocate for themselves. For example, the descriptions we heard of ways in which individuals were unable to influence or change the systems that recorded their information illustrate how those systems, and the processes they are part of, do not allow space for individuals to control the data systems hold about them. Furthermore, as digital systems enable easy sharing of data, refugees have limited ability to control where their data goes. We heard many people describe their surprise and concern about how organizations had shared their personal data with others.

We also acknowledge the bias towards refugees’ perspectives in our study. The goal of our work was to examine refugees’ experiences with, and perspectives on, the digital identity systems that humanitarian organizations use to collect and manage their personal data. As such, we did not talk with organizations to understand their side of the story, and acknowledge that many of the challenges our data surfaced engage with complex, nuanced, and non-trivial issues that organizations work to try and overcome.

6.6 Participation

Finally, the quality of participation refers to valuing participatory processes that lead to the creation of interactive systems [8]. In our research, the design of digital humanitarian systems generally followed a top-down approach, focusing on organizations as the users of such systems, catering to the organizations’ needs, priorities, and perspectives, and making refugees legible in ways determined by those organizations. But our study shows that refugees themselves are also an important category of “users” of these systems, with different needs and priorities than organizations. Unfortunately, the design of current digital identity systems has not prioritized the participation of refugees, leading to challenges for refugees as they seek to establish and manage identities via these systems.

We hypothesize that participatory methods, in which refugees are treated as active contributors to the design of humanitarian systems, might result in many benefits for both organizations and refugees. For example, the increased confidence in systems that better account for refugees’ concerns and priorities might lead to higher rates of registration and stronger protections for vulnerable beneficiaries. In addition, there might be increased efficiency due to more accurate data as refugees work to maintain up-to-date records; or there might be resource savings that result from a transfer of the effort required to perform data management from organizational staff to individuals. Of course, beyond the benefits to organizations is the greater control and dignity for refugees themselves that would result from systems designed around their needs and interests.

Encouragingly, and based in part on our work, the UNHCR has recognized the need to be able to consult better with refugees and other displaced populations on issues of digital identity. Over the past few months, our team has engaged with the UNHCR in a project to design a participatory toolkit that will provide refugees with opportunities to participate in the design or customization of UNHCR systems deployed in their specific country or context. The toolkit will facilitate consultations with refugees on key issues, including their views on registration and identity management, recommendations for improvements, identifying different experiences, including differential access or discrimination (e.g., for refugee women and girls), privacy and information sharing concerns, perceptions of biometric technologies, and more.

Our early prototypes draw inspiration from prior work on participatory toolkits, such as the city of Helsinki’s Participation Game [15] that enables city employees, residents, and other stakeholders to provide input to improve the city’s operations and services. The goal is for the new UNHCR participatory toolkit to eventually become a part of PRIMES (Population Registration and Identity Management Ecosystem) [48], the UNCHR’s ecosystem of interoperable tools, which will be the digital platform for beneficiaries, UNHCR, and other partners to interact in the digital sphere.

7 CONCLUSION

This paper examines refugees’ experiences with and perspectives on the digital identity systems used by humanitarian organizations to collect, manage, and share their personal data. We show how refugees face many challenges negotiating the digital systems that render them legible to service providers, discuss strategies refugees employ to exercise agency and control within these systems, and demonstrate the impact of these systems on their social relationships. We use Bardzell’s lens of feminist HCI [8] to make sense of these challenges and suggest a starting point for engaging refugees in the design of improved identity management systems.

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