

## "So the World Will Know Our Story": Ethical Reflections on Research with Families Displaced by War

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**Abstract:** In this article we examine the ethical implications of a qualitative research study exploring the everyday mobilities of Syrian families displaced in Lebanon. The multiple methods of data collection—collaborative family interviews, children's drawing and mapmaking, GIS-tracked neighborhood walks, and activity logging—encouraged children and family voices. At the same time, these methods provide an opportunity to explore family networks, relationships, and environments that are impacting their lives in the context of war and displacement. These methods, like all research with vulnerable populations, also raise several ethical questions. Using a process of ethical reflexivity, we discuss six ethical points related to both procedural and micro-ethics. In addition to shedding light on the importance of uncovering the everyday experiences of refugees using creative methods, we suggest broader ethical implications regarding how we respectfully work with vulnerable populations while still upholding research integrity.

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## 1. Introduction

There are many unique challenges in working with marginalized populations such as those who are affected by war and displacement. These are highly vulnerable groups, often lacking rights, opportunities, and capabilities to provide for themselves and promote their livelihoods. They live in the specter of violence and danger. Conducting research with such groups presents challenges because the population may be constantly moving from place to place due to a range of geopolitical forces. And this is not a homogenous group. They may speak a variety of languages, come from all levels of educational backgrounds, engage in

a range of cultural customs, and have experienced distinct migration experiences that may include multiple elements of adversity and perseverance (MERRY, LOW, CARNEVALE & GAGNON, 2014). For all of these reasons and more, research with such populations is certainly "a complex ethical enterprise" (DÁVILA, 2014, p.22). [1]

It is no wonder that the inclusion of these populations in research projects may be limited to "protect" participants from "coercion and exploitation, or because of feasibility issues" (MERRY et al., 2014, p.62). Researchers may therefore grapple with balancing the safety of these participants versus the importance of including their voices in research that has the potential to positively affect their lives. Furthermore, research methods must be rigorous enough to capture rich data to answer the research question, while also being sensitive enough to respect the participants' wellbeing and autonomy. [2]

In this article, we discuss how research with displaced families can be both methodologically effective and ethically respectful. We use a process of ethical reflexivity as described by GUILLEMIN and GILLAM (2004) to closely examine the ethical decisions that we made in a research project with families displaced by the Syrian conflict and living in Lebanon. The overwhelming majority of these families were experiencing ongoing distress and inhumane circumstances as a result of their displacement. Most also conveyed the importance of participating in the research "so the world will know our story." [3]

We begin with an overview of how the scholarship has described research ethics with war-affected populations. This will be followed by a description of a recent research study with Syrian families displaced in Lebanon. Using GUILLEMIN and GILLAM's (2004) process of ethical reflexivity, we describe six ethical points that we encountered in the course of conducting the research. In the second half of the article, we reconnecting to the literature to outline the ethical point and the process we engaged in to address it. [4]

## **2. Overview of Research Ethics with War-Affected Populations**

We first draw upon the established ethical frameworks that "require researchers to respect the autonomy of individuals or protect those with developing, impaired, or diminished autonomy; to safeguard the welfare of research participants and minimize the likelihood of harm; and to treat all people with equal respect and concern" (MERRY et al., 2014, p.63; see also MACKENZIE, McDOWELL & PITTAWAY, 2007). According to MERRY and colleagues (2014, p.63), these principles require researchers to pay special attention to participants in vulnerable circumstances such as "those with insufficient power, intelligence, education, resources, strength, or other attributes to protect their own interests." Ethical frameworks also mandate the attainment of voluntary and informed consent, the upholding of privacy, the safeguarding of information, and a balance between risks and benefits. However, these ethical frameworks provide spotty guidance on how to consistently uphold ethical integrity and address a variety of unpredictable ethical challenges within research with vulnerable populations. [5]

GUILLEMIN and GILLAM (2004) suggest two types of ethics in research: procedural and microethics. Procedural ethics usually involve approval from relevant ethics committees to conduct research with human participants. This process is described as a formality that must be completed in order to start a research project. It involves going through an ethical "checklist" of potential concerns, even though these concerns may be irrelevant to the specific research context. Furthermore, procedural ethics do not always provide proper oversight to conduct effective research with refugees in volatile settings. [6]

Researchers have argued that procedural ethics have been imposed upon qualitative research from the outside (VON UNGER, DILGER & SCHÖNHUTH, 2016). And others have claimed that procedural ethics in research with vulnerable populations may lean towards being overly burdensome, paternalistic, and irrelevant (ALEXANDER, 2010; EDWARDS, KIRCHIN & HUXTABLE, 2004), especially in non-Western and volatile settings. In fact, strict adherence to procedural ethics presents researchers with a catch-22 of sorts, where the onerous ethical processes can hinder research with vulnerable populations, thereby rendering them voiceless in sharing their stories with the world. [7]

A second form of ethics, or microethics, is less formal and involves everyday ethical issues, or "the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research" (GUILLEMIN & GILLAM, 2004, p.262). These "ethically important moments" (Ibid.) are especially relevant in the context of research with vulnerable populations, when subtle elements of discomfort and distress may arise in unexpected ways creating "delicate situations" (KELLEHEAR, 1996, p.97). Though there is little written about microethics, it is a regular occurrence in research with war-affected people. [8]

By distinguishing between these two different dimensions of ethics in research, GUILLEMIN and GILLAM (2004, pp.262-263) suggest that reflexivity can be used as an ethical tool to understand "both the nature of ethics in qualitative research and how ethical practice in research can be achieved." In this context, reflexivity "involves critical reflection of how the researcher constructs knowledge from the research process—what sorts of factors influence the researcher's construction of knowledge and how these influences are revealed in the planning, conduct, and writing up of research" (p.275). It is through this reflexive lens that we conduct our analysis of the ethical issues that arose in our research project with Syrian families. For this article, we include reference to the procedural ethics while giving priority to a discussion of the everyday microethics. We thereby add to the ongoing discussions about conducting ethical research with vulnerable populations. [9]

### 3. Overview of Research Project

In the following pages, we engage in a process of ethical reflexivity using the example of a recent research project with Syrian families displaced in Lebanon. The purpose of the research was to understand the experiences and mobility patterns of these families. The research was funded by the Canadian Social Sciences Research Council, with data collection taking place from 2016 to 2017. The project received human ethics approval from Wilfrid Laurier University's Research Ethics Board (#5013). [10]

We conducted collaborative family interviews with 268 individuals within 46 families who had fled Syria due to the ongoing conflict that has wracked the country. The families had "temporarily" resettled in three regions of Lebanon: northern Lebanon, Beirut, and Bekaa Valley. Families included index family members (e.g., the "nuclear" family, or mother, father, children) and extended family members (e.g., aunts, grandmothers, cousins, etc.). [11]

To start each interview, the research team gathered demographic data about the family, which also included the research team's reflections on the research process. Discussions during the family interviews consisted of life in Syria before the war, making the decision to leave Syria, the journey from Syria to Lebanon, life in Lebanon, and dreams for the future. Interviews used place-based methods that sought to understand the research participants' connection with their social and physical environments. Children participated in the research through drawing, mapmaking, and narrative methods. During the family interview, we provided time and space for the participants—both adults and children—to ask us questions about our backgrounds, our interest in this topic, as well as more specific questions about the research design and goals. We also asked participants what they thought about certain questions and processes of the research design to ensure their feedback throughout the process. [12]

Once the collaborative family interview was complete, we invited the children to take us on a walk of their neighborhood communities (with parental consent and child assent). During the walk, the children were asked to carry an activity logger, a small device that collects geographic information systems (GIS) data regarding physical movement. During the neighborhood walk, children were encouraged to show us the places where, for example, they were allowed to visit, places where their daily activities occur, and places where people they know are located. Children were also asked to indicate any important places that we should take a photo of. Throughout the course of the walk, the children had full control over the research process. [13]

After the neighborhood walk, the research team asked three family members (one parent, one older child, and one younger child) to carry the activity logger for a period of one week. Like the use of the activity logger during the neighborhood walk, GIS technology registered the family members' movements over the course of a typical week, thereby serving as an ethnographic mechanism by which to better understand their experiences. To aid in recall, family members were asked

to keep a simple diary of their daily activities while carrying the activity logger. In addition to observing the family members in environments of displacement, the GIS technology yielded quantitative data on elements such as time spent outside the home, distance traveled, etc. [14]

At the end of the one-week period, the research team re-visited the family for a follow-up interview. During this final interview, the family were asked to reflect upon their experiences over the past week and to share anything else that they did not get a chance to share during the first interview. [15]

In addition to family interviews, we conducted three focus group discussions with Lebanese community workers and Syrian refugee outreach volunteers, as well as three semi-structured interviews with individuals who were working directly with Syrian families in Lebanon. The research also included elements of participant-observation of field agencies working with refugee families, attendance at meetings with aid organizations and local community-based organizations, and visits to informal settlements and other places refugee families were living. Finally, all members of the research team were all invited to participate in a semi-structured debrief interview to reflect upon their experiences and to provide recommendations for future research. [16]

With participants' permission, interviews were audio-recorded, translated, and transcribed prior to data analysis. Data analysis was facilitated through Dedoose, an online research and evaluation data application. Data were analyzed through careful reading and collation of transcripts to ascertain meaning and significance that participants attributed to their experiences. In addition to the rich quantitative data gleaned from using GIS technology, qualitative transcripts were coded and concepts were generated and categorized into themes. [17]

Further details about the method are elaborated upon below in the reflexive analysis, which we have organized according to six ethical reflection points. Of course, this kind of research conjures a multitude of ethical issues which we could discuss at length. However, for the purposes of this article, we will limit our discussion to the following six. [18]

## **4. Ethical Reflection Points**

### **4.1 Working with student-researchers**

Conducting research with war-affected populations often requires a research team with diverse skills related to language and culture. However, working with a professional research team poses challenges related to cost, scheduling, etc. (LEE, SULAIMAN-HILL & THOMPSON, 2014). Therefore, we determined that training student-researchers to collect data was a more feasible option. As recommended by LEE and colleagues (2014), the student-researchers were selected for this project because they brought important skills to the research team. They were all bilingual (Arabic- and English-speaking) students from various disciplines such as biology, psychology, and nutrition at the American

University of Beirut in Lebanon. All had taken courses in either human development or war-affected children. All had been raised in the region, most were raised in Lebanon (which has a dialect and culture similar to Syria), two were from Syria themselves, and most had already volunteered to work with Syrian refugees in other projects. [19]

Prior to data collection, all student-researchers successfully completed the Canadian Tri-Council Policy Statement (TCPS2) Tutorial Course on Research Ethics (CORE), thereby familiarizing themselves with the requisite procedural ethics. Since the research received human ethics approval from a Canadian university, all those involved in the research project were required to obtain an ethics training certificate from either the TCPS2 CORE or an equivalent program. Due to the ease of accessing the online training program, all student-researchers agreed to complete the TCPS2 CORE. Furthermore, they all participated in a three-day workshop led by the principal investigator and covering practical aspects of the research methods, addressing sensitive topics, maintaining privacy and confidentiality, demonstrating empathy, and using appropriate terminology. They were also taught the importance of introducing sensitive topics to participants without hiding the intent of the research (LEE et al., 2014). [20]

During data collection, we followed the INTER-AGENCY STANDING COMMITTEE (IASC) (2014, p.42) "Recommendations for Conducting Ethical Mental Health and Psychosocial Research in Emergency Settings" that suggest "researchers work in pairs to ensure the actions of one researcher are monitored by another and can offer peer support and advice." The IASC (2014) *Recommendations* also stress the importance of continuing communication through debriefing about the progress of the study and what has been gained from research participation. During all stages of the data collection process, student-researchers kept in contact with the Lebanon-based research coordinator and the Canadian-based principal investigator via WhatsApp messenger, which allowed for consistent and immediate support. No data nor any identifying information about the research participants was shared over WhatsApp. Through this form of communication, the team dealt with ethical dilemmas and practical challenges as they arose. A group debrief was also conducted with all of the student-researchers at the end of the research project. [21]

From the start of the research project, we recognized that the student-researchers were not merely neutral observers, but were also involved in the *production* of research, bringing their social location to the data collection and transcription process (MACKENZIE et al., 2007). Nationality represented a strong element of power imbalance between the student-researchers and the participants. The student-researchers were all Lebanese citizens or holders of Lebanese visas; the research participants were non-citizens and in many cases not even legally registered as refugees with United Nations High Commissioner for Refugees (UNHCR), which, if registered, would provide an element of protection. The students had protection as a result of their citizenship status providing them with safety and power, a position not conferred upon the Syrian refugees they were interviewing. [22]

Especially relevant to the data collection process, the student-researchers influenced how questions were asked and the direction of the interview (LEE et al., 2014). To reflect upon this process, all student-researchers were invited to participate in a closing interview with the principal investigator. This conversation was recorded, transcribed, and used as another layer of data for the research project. The student-researchers were generally positive about their role in the research project and were able to connect the experience to their own career goals. They acknowledged their capacity to provide insider knowledge that balanced outsider positions of research adding depth of perspectives to the research (ibid.). But even though they were a part of the culture of the research participants, they had never been exposed to the kind of distress that the Syrian families brought to the data collection process, thereby posing multiple "ethically important moments" (GUILLEMIN & GILLAM, 2004, p.262). Student-researchers reflected upon these moments as times that they struggled with what to do, with some feeling pressure (and helplessness) to actively respond to the families' stories by "fixing" the situation of the family and even taking action to improve the national and international "systems" that were contributing to the families' suffering. [23]

#### 4.2 Recruitment

Recruitment of participants may raise multiple procedural and microethical challenges. The IASC (2014) "Recommendations" state that selection of participants in emergency settings needs to be equitable and as inclusive as possible so as not to inadvertently send a message about who is and is not being heard in research projects. For persons in desperate situations, especially when the community organizations and research team have more power, the voluntariness of participation may be compromised (MACKENZIE et al., 2007). [24]

In our study, and aligned with various procedural ethics frameworks, initial recruitment of Syrian families took place in partnership with various community and international organizations working in northern Lebanon. Including these organizations in recruitment process can provide viable access to the population of interest, while also offering assurances to ethics committees (MERRY et al., 2014). When relevant, our research team visited the *shaweesh*, community leader, who introduced us to any available families who would be interested in participating. [25]

MACKENZIE et al. (2007) discuss power imbalances within refugee communities, noting that assumptions of cultural homogeneity increase these power imbalances. Organizations or community leaders may decide which families receive assistance. This, in turn, may affect voluntariness due to fear of services being withdrawn or altered as a result of participation or lack of participation (IASC, 2014). This may create a context in which recruitment of participants by those in power (e.g., community organizations or *shaweesh*) can be problematic. At the same time, it is also critical to engage with community organizations and leaders in order to effectively enter the community and build trust between the

research team and the research participants. This represents yet another catch-22 in conducting research with vulnerable populations. [26]

To address this ethical issue, we repeatedly emphasized to the community organizations, the *shaweesh*, and the families that there was no pressure to participate. Procedural ethics indicates that this explanation is sufficient. However, we also recognize that even though participants said they were participating voluntarily, they may have had unspoken reasons for participating. Of course, in our study (as in many related research projects), these reasons included false expectations of support or remuneration (IASC, 2014; MACKENZIE et al., 2007) or cultural norms related to hospitality that promote saying yes (IASC, 2014). Some families indicated they wanted to participate, because they were bored of the monotony of displacement and were interested in giving their children something to do. While other participants told us that they wanted to share their stories with the world in the hope that the research would change their situation. [27]

### 4.3 Privacy and formality

Issues of privacy and formality have been raised in many ethical commentaries on refugee research (IASC, 2014; JACOBSEN & LANDAU, 2003; MACKENZIE et al., 2007). Procedural ethical guidance advises researchers to assure participants' safety, do no harm (HUGMAN, PITTAWAY & BARTOLOMEI, 2011), respect autonomy (MACKENZIE et al., 2007), engage in a process of interactive informed consent, maximize data protection, and avoid personal identification in the research process and reporting (IASC, 2014). But the reality of conducting research with refugee population poses risks to participants that challenge these procedural ethics. The safety and anonymity created by the prioritization of privacy and confidentiality in procedural ethics can be insufficient to assure safety. In some cases, it can be potentially dangerous for some participants. [28]

Traditional human subjects research, including qualitative research, has tended to favor privacy and the use of a research space somewhat removed from living spaces. For example, the researcher invites a participant to be taken aside, to meet in a prescribed private space where nonparticipants cannot intrude or listen in or observe. This space is often separate from the participants' living or work situation (although in qualitative research it is usually nearby these spaces, and in some cases in the home). In refugee research, this space is often a refugee camp office, a mobile trailer, a camp classroom after hours, or an unused clinic room. The separate space is used to get uninterrupted reports, to facilitate an open conversation, and to ensure that personal information remains confidential. [29]

However, this process is potentially fraught with risk and pressure. In often crowded and watchful refugee settings, the act of entering a private space with a research participant can be a very visible and public act. Others living in this environment will likely know that a member of the community is engaging in a private discussion. The situation could be threatening to community members who suspect that the participant is getting special treatment from which others in



the community will not benefit. Or they may suspect that information is being divulged to outsiders without the participation and oversight of the entire community. Indeed, refugee communities are often keenly aware of who is talking to the "people with clipboards" who visit refugee settlements. The act of having a select few speak privately to outsiders poses risks that the research participants will not adequately represent the community experiences. Thus research conducted in refugee settings that attempts to be formal and private might be neither, and thus could increase risks to participants and the research team (IASC, 2014; JACOBSEN & LANDAU, 2003; LEANING, 2001; ZWI et al., 2006). [30]

In our research, data collection was more informal and public. Akin to naturalistic research (ANGROSINO, 2016), participants were invited to be interviewed in their living situations, community centers, or out in the open within the refugee community. But the refugee context is not a natural setting for refugees, and hence participants may still not have confidence in speaking in the presence of others. They are safe from the envy created in formal privacy, but not necessarily able to safely reveal private information with family members and neighbors present. [31]

This raises issues of free consent and participant accuracy. Participants could be under pressure to provide stories that might get them more attention from the aid community. This has occurred in other war-affected groups to the point of providing false narratives (BEECH, 2018; HILHORST & DOUMA, 2018). Participants could be under pressure to report certain vulnerabilities, to report the situation of the community as a whole, to emphasize group needs but not individual needs, to distort information about some conditions, or to create a false narrative if that narrative is believed to increase the chances of receiving additional aid. [32]

Although we do not specifically discuss the ethics regarding how individuals and families construct their personal narratives (GERGEN & GERGEN, 1988; POLKINGHORNE, 2010; SARBIN, 1986), we recognized in this research that the stories we were collecting had elements shared both within and among families in the area. Our method allowed for the families to tell the stories that they felt comfortable sharing with us, without challenge, understanding that these stories likely had personal, familial, and communal elements. [33]

#### **4.4 Confidentiality**

Confidentiality is very much related to issues of privacy and formality. In this research project, we considered two aspects of confidentiality: confidentiality *inside* and *outside* the refugee community. First, to uphold confidentiality inside the community, researchers should try to provide participants with as much privacy as possible, while recognizing the limits, such as those discussed above. Second, as will be discussed in this section, researchers have much more power and an obligation to preserve confidentiality outside of the community, particularly in regards to data. If participants' personal details are disclosed outside the community, participants may be targeted. For example, at the time of the data

collection in 2016, at least four combatant groups (including pro- and anti-government forces) were monitoring electronic media and communications in the region (a situation of which both the researchers and participants were aware). These groups may not have been interested in our research project, but they were certainly intolerant of possible betrayal or conveyance of information that could affect them (whether coming from participant or researcher). Thus in our research, data that could potentially identify the participants included lists of names, transcripts, GIS data, audio files of recorded interviews, and photography. If not safeguarded, any of these data could be used to identify participants. [34]

In the current study, we addressed the issue of confidentiality within the community by conducting our research in living situations with less privacy than many traditional approaches might prefer. We conducted our interviews in tent spaces and rooms where we could have a some uninterrupted and private meetings, but this was defined more by the preference of the participants rather than a demand of the researcher. We met participants in places they felt comfortable to have discussions with outsiders. Family members could speak rather freely, but non-participant families nearby were often fully aware that outsiders were visiting and interviewing. Children were playing in and around the same rooms and tent spaces, and often friends and non-participant family members would come and go as our interviews progressed. The settings where Syrian families were living in Lebanon was particularly suited to this design. Our research sampled from families who were living in crowded informal settlements, apartments, and houses throughout three different regions of Lebanon. These living situations afforded some privacy while also including some relatives and friends. The living situations usually included front areas for guests and dining, makeshift doors, and enclosed areas for family privacy. Neighbors, friends, relatives, and community workers could visit, but each family had their own space where they could receive guests with some level of privacy. But in almost all our interviews, family members, friends and neighbors knew of the interviews, their purpose, and at times their content. [35]

The research team aimed to provide comfort and appropriate information through the informed consent process, in which participants were asked to share only what they were comfortable with. As per guidelines for procedural ethics, the research team explained and reiterated data handling assurances. [36]

The research team requested to conduct the collaborative family interview in a private space of the family's choosing. The collaborative family interviews research required the participation of at least three family members per family: one parent, one older child, and one younger child. But, oftentimes, both parents were present, as well extended family members such as grandparents, aunts, uncles, and cousins. They became participants and observers in the interview setting, and they were thereby included in the informed consent process. [37]

The interviews were designed so participants could attend to everyday, family-related interruptions. For example, tea was often served, babies cried and were breastfed by their mothers, and cell phone calls were answered. At times other

relatives would check in, indicating that they understood there was a research interview in progress. In most cases, the participant families had clearly told them that researchers were visiting. At times, friends and neighbors would bring groceries, find out what the researchers were doing, or ask about the family's ongoing activities. [38]

These interruptions were treated as natural family activities that became a part of the naturalistic approach to the data collection process. Invariably these interruptions were normal and even expected, because they were simply part of ongoing family life in Lebanon. When interruptions occurred, the research team would stop the interview process, because the newcomers had not engaged in a process of informed consent. Usually the participants (rather than the research team) would politely request some privacy to continue the collaborative family interview. At that point, most of the visitors would graciously leave, just as they would if they were interrupting a family with dinner guests. In this way, the families had the comfort of their living situation, the ability to decide what they would disclose, the power to manage the conversation in their own living situation, and a well-understood understanding of data confidentiality and safety from identification threat. [39]

Once these interruptions were attended to, the family members easily returned to the interview space. Comfort was emphasized. Outsiders were usually aware that an interview was occurring, understanding that the interview was about the flight of the family and their current situation. If the participants were comfortable, neighbors and friends joined the interview process. In some cases, participants indicated that they were uncomfortable with sharing these experiences in front of neighbors, and so the interview was casually discontinued until neighbors left and the participants felt comfortable again. [40]

Because the child-led neighborhood walks—in which the children led the research team on a walk of their community—took place outside, they were also typically observed by the community. Most community members were aware that there was a research team present, the nature of the research, and the elements of the research methods. [41]

In follow-up interviews, no family member ever indicated that the community had received us negatively. The activity loggers were at times misunderstood, shut off, or returned unused. This was due to families not understanding the purpose of the activity loggers, feeling that the activity loggers would be lost or damaged, or fearing that others not involved in the study would misunderstand their use. Ultimately, the family visits resulted in no repercussions from the participants' family or community. In the context of the informal refugee living situations in Lebanon of 2016, the researchers were welcomed guests. [42]

All of the above illustrates the challenges with ensuring confidentiality within such a setting. In our research project, the families did not have complete confidentiality within the community. Their living situations were such that any visits were known by surrounding families. The participants and the research

team found themselves in a position to explain the research to outsiders. The focus of the research—experiences of Syrian families who were displaced in Lebanon—was neither unusual nor off-putting, for most everyone in the community was displaced from Syria. Therefore, no one was particularly singled out for any particular type of research information. They all understood that we were interested in learning about the family's story. Ultimately, participant and non-participant families alike were thankful that, as one father stated at the end of the collaborative family interview, "someone is listening to what we are going through." [43]

#### 4.5 Sharing stories

Research with refugee populations often involves discussion of one's history before and during conflict. That history may include memories that evoke sadness, loss, stress, harm, and trauma. There is a legitimate concern that the re-telling of one's story can result in re-traumatization (BELL, 2001). Indeed, participants in the current study often told us of terrible experiences that had happened to them, and many cried and showed sadness about these stories. Yet, a systematic review of therapies for post-traumatic stress disorder (PTSD) that involved such retelling found that any arising distress is short-term (APA, 2017). In the longer term, re-telling in a safe and conversational context may be psychoeducational, relieving, and an important part of symptom reduction (ibid.). In fact, the re-telling of distressing events, combined with supportive therapy, is associated with positive outcomes (GWOZDZIEWYCZ & MEHL-MADRONA, 2013; HIJAZI et al., 2014). [44]

The current study was neither described nor intended to provide psychotherapy, though aligned with procedural ethical norms, we provided families with a list of local psychosocial supports. We did respect the comfort that is intended in therapeutic retelling, by offering a safe but informal setting in relative privacy. We were careful to request participants' stories of flight in a setting that was comfortable for them. We assured participants that they could refuse to tell any story they were uncomfortable with or stop the research at any time. In addition to assuring full confidentiality, we asked all participants to only share information that they were comfortable relating to us. In this manner, participants were empowered by a personal decision buffer to exercise their own autonomy and filter parts of their story that could be difficult for them to re-experience or tell. [45]

The resulting narratives in many cases were detailed, rich, and emotional. Distressing stories were told with emotions such as sadness or crying. The telling of these stories was often followed by relief. At the end of the interview, 37-year-old Umm-Adib,<sup>1</sup> mother of nine, stated, "I would like to thank you for visiting us. You made us feel better, because you listened to our stories and to what we had to say." Likewise, 44-year-old Umm-Mahdi said, "It feels good when someone talks about and brings out the issues. ... It feels good when someone asks me

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1 All names are pseudonyms. In Arabic culture, after the birth of the first child, parents are given the honorary title of *abu* (father of) and *umm* (mother of), followed by the name of the first-born son. We have used these identifiers throughout the article to indicate fathers and mothers.

questions and I answer." These examples illustrate how some families admitted that they had never shared these stories before, and they were glad to have shared. Others felt empowered to be asked to tell their stories, because they felt that their stories had been neglected both within and outside their communities. Syria has a long cultural history of storytelling, and a number of families in our story indicated their stories were formative parts of their family past and future. The opportunity to share, and the act of sharing, was explicitly appreciated by a majority of the families. [46]

Per ethical guidelines, participants were reminded that they could exercise their right to skip certain questions that they felt uncomfortable answering. When asked about her journey from Syria to Lebanon, 37-year-old Umm-Zahra interrupted and asked the researcher to "leave this question." However, when most participants were reminded of this, they tended to want to continue. For example, 31-year-old mother of eight children, Umm-Anwar, started crying when describing her home in Syria. The student researcher responded by explaining: "Remember that if you don't feel like answering any question, that's your right." Umm-Anwar replied: "No, I have no problem. On the contrary, this conversation gives us hope." If the participant did not want to continue with the line of questioning, which we found to be rare, our method was sufficiently fluid to allow us to move forward comfortably in the interview to address other topics. [47]

Most participating families had been displaced within Lebanon for four to six years and were contending with high rates of poverty, economic precarity, discrimination from the Lebanese authorities and local community, food insecurity, and community violence (AKESSON & BADAWI, in press). These dire circumstances made one father feel as if "we are barely surviving here." These families said they were glad that they could be involved in the study because they felt ignored and forgotten by the international community. They felt that their participation gave them a voice. The father mentioned above asked us to interview him and his family "so the world will know our story." When we informed the father that the children would be getting some toys for their participation, he replied by saying that telling his family's story was "all the reward we need." [48]

Research with refugees can respect their privacy, ensuring their autonomy and power over what they wish to reveal. Simultaneously, such research can and should empower them to speak out and share their stories. [49]

#### **4.6 Representing stories**

Reinforced by the words of many of the participants to "share our story," we have made the dissemination of our findings a priority. After completing data analysis, we have begun to engage in multiple methods of knowledge mobilization to share these experiences with a broad audience and potentially affect change. However, by representing the research participants descriptively in order to change the social world and systems, we raise additional issues of "representation ethics" (DÁVILA, 2014, p.28). In other words, is it ethically responsible to represent the

research participants in a certain way, because this will lead to improvements for these populations? [50]

But there are also several ethical cautions when disseminating research. Drawing upon the work of GOODALL (2000), DÁVILA (2014, p.29) argues that all research representations are inherently "partial, partisan, and problematic," but that it is nevertheless important to engage in this discussion. Indeed, the research team has power as their interpretations of participants "might edify them, render them voiceless, or essentialize them" (p.22). Representations of research participants could "potentially fuel anti-migration rhetoric (e.g., terrorism, spreading disease, draining resources, criminality) further raises the debate as to whether certain migrant groups should be studied" (MERRY et al., 2014, p.72). Dissemination can also reinforce dominant representations and/or perpetuate stereotypes contributing to learned helplessness and thereby impact aid (IASC, 2014). Furthermore, MACKENZIE et al. (2007) discuss cases in which researchers have disseminated information leading participants to be in positions of danger, creating a mistrust of research. [51]

There are several ways that researchers can combat these ethical challenges in dissemination. First, there is an ethical balance between sharing participant stories versus maintaining confidentiality. For example, the IASC (2014) *Recommendations* argue that dissemination needs to occur in a way that is accessible and inclusive, but maintains confidentiality. For confidentiality in dissemination, researchers can make efforts to mask the data without compromising the integrity of the data. For example, the IASC "Recommendations" suggest using pseudonyms, case numbers, and creating composite persons, where a person is "made-up" and based on features of different people. In our project, we have masked the data by depicting scenes as illustrations instead of photos, thereby eliminating any identifiable information. With the GIS data, we have included large areas rather than specific details in order to hide any specific geographical locations of participants. [52]

But there is also an issue of representing the individual and unique experiences of the participants rather than treating them as a homogenous group with collective experiences. For example, DÁVILA (2014, p.26) suggests referring to "Lin's portrait of life in a refugee camp" versus "Vietnamese Central Highlanders' experiences in refugee camps." Indeed, there are many commonalities among research participants. Their inclusion in the sample is based on their experiences as Syrian refugees living in Lebanon and this commonality is justification for their inclusion in the study. But the unique humanity of the individual may get lost if a participant is grouped in this way. Therefore, in our dissemination strategy, we have created individual vignettes of each family highlighting their unique examples of struggle and perseverance. At the same time, in the spirit of confidentiality, we have eliminated or slightly modified any identifying information about each family. We also made efforts to provide individual pseudonyms for each of the 184 participants rather than referring to the participants generically as "Boy15" or "Mom35" (KAISER, 2009). [53]

Conducting research with displaced populations poses additional challenges to ensure that dissemination is driven by the participants. First, war-affected populations such as those in this research project are not always easily accessible due to their inherently precarious and mobile status. Second, participant-driven dissemination may not be realistic in certain formats such as academic publications. [54]

Despite these challenges, when possible, for effective and ethical dissemination, it is important to establish means of feedback to the community regarding the research (MACKENZIE et al., 2007). Inclusion of community organizations in the recruitment and sampling process can "maximize the dissemination of study results back to participants" (MERRY et al., 2014, p.73). DÁVILA (2014) notes that even though the research may fully engage in collaboration with the research participants, the researcher is still the one who decides which stories will be shared and which ones will be excluded. But researchers still need to make efforts to consult with participants about data dissemination as one way to triangulate the data and honor participants (ibid.). However, engaging with the participants in a meaningful way might be a challenge when those participants are a mobile population. [55]

Finally, collaboration with practitioners and policymakers is vital to ensuring that the research can be used as a means of advocating for improvements in the lives of the research participants. MERRY and colleagues (2014) indicate that the research stages of data collection, analysis, dissemination, and recommendations for changes to practice and policy must all work together in concert and "must be consistent with ethical norms and principles, social values, and legal and other regulatory frameworks" (p.73). [56]

## **5. Discussions and Conclusions**

There has been concern that research with refugees should be highly structured in order to provide ethical assurances (JACOBSEN & LANDAU, 2003; ZIERSCH, DUE, ARTHURSON & LOEHR, 2017). These highly structured ethical mechanisms provide frameworks for procedural ethics, ensuring that the research team anticipates any unforeseen and adverse effects related to the research. Not covered in these frameworks are the everyday ethical issues, or micro-ethics, that arise when doing qualitative research, which can oftentimes be messy and informal. But according to GUILLEMIN and GILLAM (2004, p.269), the chasm between these two types of ethics is not so wide: "there is considerable continuity between ethical concerns at the procedural and practical levels and moreover, there would be something drastically wrong if this were not the case." Based upon our experience with the research, we believe that procedural ethics provides us with an understanding of the importance of ensuring that we upheld high ethical standards throughout all stages of the research, from sampling to dissemination. While at the same time, we found that it was important to remain flexible and embrace informality, especially when this would promote the autonomy and dignity of our participants. In this way, we toggled between procedural and micro-ethics to create methods that were

ethically rigorous and providing reassurances aligned with procedural ethics. At the same time, the methods were flexible enough to obtain quality data from participants who wanted to participate "so the world will know our story," thereby fulfilling our research objective of learning about the everyday experiences of these families. Finally, the methods met JACOBSEN and LANDAU's (2003) dual imperative of research with refugees by being both academically sound and relevant to enact policy change. [57]

We trained and supported a research team that would be sensitive to the cultural and ethical issues that arose in the course of data collection. We encouraged a flexibility and informality in the data collection process, while still aiming for a rigorous data collection process. Despite the informality involved, we found that participants determined the physical space they felt comfortable sharing their rich and powerful stories of loss, flight, and the transition to survival. The reflexive informed consent process and data handling reassurances gave participants many choice-points to decide on what they wished to tell the researchers, thereby honoring their autonomy. The research topics (life in Syria, flight from Syria, geospatial activity within Lebanon, and future dreams) were a common denominator among friends, family, and neighbors, many of whom knew each other's stories. Therefore, eliciting these stories posed little friction between participants and non-participants. The naturalistic approach of meeting the participants within their everyday environments was clearly comfortable and safe for the participants. We were therefore persuaded that such an *in situ* approach to interviewing is safer and more appropriate for the refugee context than structured meetings where they are removed from the only community they have in the midst of displacement. And as we move towards the dissemination phase of the research, we are cognizant of the importance of involving the research participants in the representation of their stories. [58]

Finally, though in this article we focused on research with a specific cohort of Syrian families, the ethical reflection points may be relevant to research with other populations such as marginalized populations living in unstable settings. Our reflection reminds us and ensure that research with such populations should always respect the inherent dignity and worth of research participants, as well as their families and communities. [59]

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