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Research with Refugee Children, Youth, and Families: Ethical issues

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Research with Refugee Children, Youth, and Families: Ethical Issues

Mehrunnisa Ahmad Ali Toronto Metropolitan University

Series Editors: Anna Triandafyllidou, Richa Shivakoti, and Zhixi Zhuang



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Abstract

Doing research with refugee children, youth, and families is fraught with ethical challenges because most researchers and Research Ethics Boards in the Global North are relatively unfamiliar with this population and their situations. Traditions of research ethics in these countries are first discussed, followed by a focus on refugees in general, and then specifically on refugee children and youth. Various dimensions of ethical research are examined, with examples drawn from research with refugees. The paper concludes by urging scholars to undertake this kind of work despite its challenges because excluding refugee children, youth, and families from research would be even more unethical.

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Introduction

Doing research with children, youth, and families seeking refuge is fraught with ethical issues (Bloemraad & Menjivar, 2022; Bose, 2022; Clark-Kazak, 2021). Researchers in the Global North¹ typically do not share with refugees a language, culture, socio-economic status, or the experience of seeking refuge in another country. They usually do not have prior experience in working with families who have lost their homes, livelihoods, and communities, or with children and youth who have lost their familiar environments and sources of support. Contexts in which they engage with refugee families add layers of complexity to their work. Refugees, highly dependent on others for their survival, may expect or explicitly ask for help from researchers, who they perceive to have access to funds, useful information, translation, and advocacy skills (Bilotta, 2022; Vervliet et al. 2015). Further, researchers may want to help them for humanitarian reasons but also want data from them, which complicates their relationship.

Although research with refugee families, including children, is not a new phenomenon (see Pieloch et al., 2016), it grew rapidly in the aftermath of the Syrian civil war, especially in Canada and Germany. Following the internal violence in 2010, refugees from Syria moved in large numbers, first to neighbouring countries, and then to parts of Europe and North America. In Canada, a new government was elected in 2015. Keen to project its image as an internationally engaged party, it offered to bring in 25,000 Syrian refugees in four months (Government of Canada, 2020). Germany, under the leadership of Angela Merkel, admitted more than 800,000 refugees within a similarly short period of time, despite resistance from some political parties and other European countries. To understand how the refugees were faring and how local populations were reacting to their arrival in such large numbers, policymakers, practitioners in the social services sector, and academics in both countries became interested in research focusing on refugees. The Government of Canada funded 27 such studies in 2016. Several related to the evaluation of humanitarian aid program were also commissioned in Germany. However, hardly any of them discussed ethical issues of research with refugees, especially with reference to children, youth, and families.

A small group of German and Canadian researchers, connected by their membership of the Children and Youth Refugee Research Centre (CYRRC),² became interested in ethical issues related to work with refugee families. Some of us consulted codes of ethics produced by the Refugee Studies Centre at Oxford University, the Centre for Refugee Studies at York University in collaboration with the Canadian Council for Refugees, and the Canadian Association for Refugees and Forced Migration Studies. Others examined guidelines developed by the International Association for the Study of Forced Migration (IASFM). We found useful advice and important principles in them, but still needed granular details about how to navigate the muddy terrain of ethical research with refugee children, youth, and families. We collectively decided to write a book (soon to be published by UBC Press) to pool together insights we have gained from working directly with these groups.

In this Working Paper I first describe some traditions that frame research ethics in general, followed by a focus on research with refugee children, youth, and families. Next, various dimensions of research ethics are discussed, pointing to multiple, intersecting, and complex considerations to be juggled. This paper does not offer any specific guidelines. Instead, it invites readers to examine all their research decisions from an ethical perspective, especially when they work with refugee children, youth, and families.

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¹ Although this is an ambiguous and contested term, it is widely used to identify relatively affluent countries where refugees seek asylum.

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Traditional Research Ethics

Discourses about research ethics in the Western world can be traced to the moral philosophy of the German philosopher Immanuel Kant ([1783] 2017), who described ideals of moral conduct based on what he believed to be universal human values. Later philosophers, (e.g. Rawls, 1993; Taylor, 1992) countered his assumption by claiming that what is 'good' or 'bad' is contextually defined and varies across time and space. This notion gradually evolved into normative ideals called 'ethics,' that were articulated, interpreted, and adopted in various professional communities, roles and relationships, including those of researchers.

Research ethics are grounded in two older traditions and several newer ones. Writing about the older traditions, Israel (2015) tells us that in the consequentialist tradition, initially associated with English philosophers Bentham and J.S. Mill, the evaluation of decisions or actions depend on their consequences. If their positive outcomes outweigh the negative ones, then they are considered ethically defensible. In contrast, the non-consequential tradition disregards consequences as the measure of decisions or actions. Those who follow this tradition believe that some principles or 'rules of conduct' are essentially good and should be practiced in all situations. Biomedical researchers coalesced around this approach, claiming that largely agreed upon principles in a society rather than specific outcomes in various cases should guide ethical decision-making (Israel, 2015). However, in the latter half of the twentieth century, scholars began to note the failings of medical research and proposed what is known as 'virtue ethics' as an alternative. According to this approach, researchers should develop a personal code of ethics, informed by their own experiences, others' examples, and reflections on them (Macfarlane, 2010). Some scholars also advocate for a situation-based approach (see Thacher, 2004) in which analogous cases, rather than ambiguous and sometimes conflicting principles, guide research decisions. They argue that research is a messy and complex process, and researchers need to consider different settings, methodologies and technologies, researchers, and participants. This position, however, elevates the risk of ethical relativism, and scholars such as Resnick (2012) suggested that experiential knowledge should be grounded in general values such as integrity, flexibility, and resourcefulness to make ethical decisions.

In the latter half of the twentieth century, issues of power-knowledge (see Foucault, 1980) became more prominent in scholarly discourses, and critical approaches to research ethics gained traction. Feminist scholars such as Gilligan (1993) and Noddings (2003) advocated for an 'ethic of care' in which engaged and caring relations between researchers and participants replaced neutral and distant relations promoted in the past. Other scholars adopted this stance to include research participants in their studies that are marginalized because of their race, ethnicity, socio-economic background, legal status, or disability. Post-colonial theorists (e.g. Tikly & Bond, 2013) suggested that costs and benefits of research for colonized people must also be carefully considered from an ethical standpoint.

Discourses such as the above led to the formation of several international agreements about research ethics. The first of these was the Nuremberg Code created in 1947 in response to the horrendous medical experiments conducted in Germany around the Second World War. This was followed by the Declaration of Helsinki in 1964, the Belmont report in 1979, the Council of International Organization for Medical Sciences in 2002, and the UNESCO Universal Declaration on Bioethics and Human Rights in 2005. These agreements focused primarily on biomedical sciences, but the more recent ones also included psychological and social studies. Many professional associations, research councils, and research institutions in the Global North began to adopt principles articulated in their research ethics statements, such as respect for participants, beneficence, and justice. However, critics of their widespread use also questioned their assumption of universality, over-simplification of complex situations, and ethical imperialism by non-recognition of colonial and neo-colonial experiences (Israel, 2015).

In Canada, a consultative group of research councils was formed in 1978 to formulate guidelines for ethical research. This eventually led to the 1998 Tri-Council Policy Statement (TCPS) on ethical conduct for research involving humans, which is used by the Social Sciences and Humanities Research Council (SSHRC). To implement this policy, Research Ethics Boards (REBs) were set up in research institutions to ensure individual and collective compliance. The TCPS was last updated in 2022 to take into account variations in qualitative studies, emergent designs, Indigenous knowledge traditions, and online data-collection. Although the changes were welcomed by some social scientists, many continue to be vexed by REB processes and criteria that delay or distort data-collection plans or are too inflexible for the fluid situations in which fieldwork is done.

North American researchers typically require formal approval from institutional REBs before they can collect data from human participants/subjects, unless the study is for program evaluation. In other parts of the world only some disciplinary units, funding agencies, or professional associations require such approvals (Bloemraad & Menjivar, 2022; Wihstutz, 2020). Those who work with refugees also have to go through other gatekeepers, such as local governments, humanitarian aid agencies, schools, healthcare centres, or childcare centres to recruit research participants. Some of these organizations ask for additional ethics approvals adjudicated by their own boards. Conflicts of interest can arise among researchers and staff of such organizations because of competing interests or priorities, and refugee families can get caught, or fear getting caught, between the two. Further, refugee children require parental approval to participate in research, and their parents' decisions may not always align with their own preference.

In Germany, institutional research ethics approval for studies in social sciences has gained more traction in the last few decades but is still not mandatory (von Unger, Dilger, & Schönhuth, 2016). Israel (2015) points out that the guarantee of academic freedom in the German constitution, a general distrust of restrictions on knowledge-generation, and the relative underfunding of research, has enabled researchers located there to act more freely than in North America. However, studies funded by federal grants, as well as some in psychology and sociology, are subject to approval by ethics committees, including those formed by professional associations. In 2008, an overarching body called the German Ethics Council was created primarily to assess biomedical research. In other countries, research ethics generally remain a matter of self- regulation in the academic community, especially in Southern, Central, and Eastern Europe (Piccio, 2016).

In the next section, I discuss some of the specific complexities related to ethical research with refugee populations, followed by a special focus on children and youth, with reference to both institutional and self-regulation.

Ethics of Research with Refugees

Most issues in ethical research with refugees can be traced to the power disparity between researchers and research participants (Clark-Kazak, 2021; Müller-Funk, 2021). People seeking refuge in other countries are likely to be citizens of low-income and/or politically unstable countries that were colonized by Europeans. When they encounter researchers who are from high-income countries, White, and associated with international agencies or universities, the power differential is amplified. Refugees from Afghanistan, for instance, are well-aware of the invasion of their country by Russians, followed by Americans and their allies (see Farr, 2020). They see researchers or institutions associated with these countries as powerful invaders in their land.

Refugees are in a situation where they have not only lost their material possessions but also their socio-cultural anchors and political-legal rights. Unfamiliar with the language and 'systems' of places where they arrive, they become dependent on others for basic human needs.

In comparison, researchers often have and/or are perceived to have high socioeconomic status and resources such as information, access to funding, social and professional networks, and communication and advocacy skills that refugees need. Power differences between researchers and the researched get amplified in this context.

Because the staff of international and non-governmental aid agencies and local governments act as gatekeepers of researchers' access to research participants, refugees may assume a relationship exists between the two (Clark-Kazak, 2021). Those who find researchers to be attentive interlocutors, call on them to act as their advocates in interactions with government representatives and service providers (Bilotta, 2020; Karooma, 2019). They try to leverage researchers' advocacy to improve their support services, which can further complicate their relationship and influence their interactions (Block et al., 2012; Bose, 2022; Clark-Kazak, 2021).

Researchers commissioned to evaluate programs and projects face additional challenges. Staff and administrators of organizations managing programs that serve refugees may be wary of researchers' judgements about individual or organizational performance. They may avoid sharing full information with researchers and discourage others from doing so, or deny access to particular persons, procedures, or documents. Because researchers are dependent on these organizations for data, as well as access to other sources of data, they may be reluctant to advocate for the refugees if they fear a defensive reaction. Bose (2022) suggests that the potential for misunderstandings, miscommunications, and tensions is high in such settings.

Research with refugees raises additional concerns. Chatzipanagiotidou and Murphy (2022) suggest that researchers' efforts to collect data from refugees can feel like 'forced intimacy,' which they are not in a position to refuse. They feel obligated to recount details of harrowing experiences, often multiple times, even though recalling these may re-traumatize them. Nevertheless, they respond to researchers as figures of authority, sometimes considering research interviews to be a part of the seeking asylum process.

Clark-Kazak (2021) points to refugees' multiple vulnerabilities related to their dependence on others for basic human needs, precarious legal status, mandatory (im)mobilization, criminalization, and heightened surveillance. She notes their encounters with hostile populations and racist, anti-immigrant policies. She questions whether, given their powerlessness, their research consent is genuinely fully informed and voluntary, and whether researchers can actually ensure their privacy, minimize harm, and maximize benefits.

Writing about the increasing demand for information about refugees, Bloemraad and Menjivar (2022) suggest that the inevitable tension between academic accountability and transparency that calls for open access to researchers' records – including data, statistical models, qualitative codes and analytical procedures, as well as contextual location details – and the risk of information leakage, especially as new technologies have made access to big data much easier. This information may jeopardize refugees' legal status and access to social services and may even put them and their families at risk of deportation or imprisonment. They caution that refugee respondents may not fully understand the terms of informed consent, or needlessly avoid participating in a study because they are intimidated by the formality of institutional consent forms.

Some scholars (e.g. Bloemraad & Menjivar, 2022; Kyriakides et al., 2018) claim that researchers' representations of refugees can also lead to stereotypes that not only affect them, but people with whom they share a nationality, religion, race, and ethnicity. Taking a long-term view, Landau (2019) warns that research on refugees could make academics complicit in strategies to control migration patterns that reproduce international inequities.

Chatzipanagiotidou and Murphy (2022), along with several other scholars (see Grabska & Clark-Kazak, 2022), raise the important question of why researchers choose to work with refugees. As noted above, governments and non-governmental agencies commission researchers to evaluate policies and programs. Researchers may choose to work with them to advocate for refugees, advance their own careers, contribute to public discourses, and influence

policy changes. Those working in academic institutions may have similar or multiple motivations, based on their interests, opportunities, and commitments.

Given the above risks, should researchers study refugees, and if so, how? The most compelling reason for doing so is that unless refugees' perspectives are systematically documented and represented, decisions that have life-changing consequences for them will be made without taking their experiences and opinions into account. Influential organizations such as the International Organization of Migration (IOM) and the United Nations High Commission for Refugees (UNHCR), national governments, and aid agencies, may make unilateral decisions that affect refugees everywhere. Given the domination of voices from the Global North in international agencies, and highly polarized political positions about refugees in these countries, it is essential to include refugees' perspectives in research about them. Refugee voices should be widely and accurately represented in the public domain so everyone can recognize them as human beings and acknowledge their rights as human rights. Clark-Kazak (2021) recommends that: researchers who work with refugees should be familiar with resources such as the IASFM, comparative guidelines from other countries, and the relevant literature made available through open access; academic and non-academic researchers and members of REBs should learn about specific ethical issues related to research with refugees; honest reflections on lessons learned from work with refugees should be widely shared; and a dialogue with underrepresented groups should be initiated in languages spoken by them. She also suggests that ethics reviews and audits should be promoted in countries where they are not a common practice, protection of refugees' interests should be prioritized when sharing data, and that they should be includes in analyses and dissemination, whenever possible (Clark-Kazak, 2021).

Ethical Research with Refugee Children and Youth

Several scholars (e.g. Clark & Richards, 2017; Murray, 2019) have suggested that children are quite capable of understanding and expressing their experiences but remain under-represented in the social sciences, especially in migration research (Ali & Gibran, 2020; Bilota, 2020). Perry-Hazan (2016) writes that social scientists tend to assume that young people's perspectives are the same as those of adults, that adults can fully represent young people, or that young people are not worthy of scientific study. He refers to such assumptions as 'adultism'. Reasons for the paucity of research with refugee children and youth may include a lack of consensus among scholars and other social structures, experiential and socio-cultural distance between researchers and refugee children, and gatekeeping at multiple levels.

According to Redmond (2003), childhood as a conceptual category emerged in Europe about 300 years ago. At the same time, institutions were created for the education, health, and social welfare of the younger members in society because families could not meet all their needs alone. Currently, the age of 18 years is generally used as an indicator to mark the end of childhood, but specific definitions and applications vary a great deal.

The distinction between childhood and adulthood is important in migration and its study. Children who may accompany migrating parents and those who must be left behind depends on the cut-off age applied in receiving nation states by different governments. For example, the age at which immigrant children may accompany their parents to Canada (without the application of additional criteria) was changed in 2017 by the Liberal government from under 19 to 22 years. The age at which children can independently choose to participate in research also depends on their location. In Europe, children above the age of 14 years can consent to participate in research but in North America they can do so at the age of 18 years. Below this age, children can only assent to participate in research, subject to their parents' or guardians' approval.

The significance of age for participation in research arises from the tension between competing imperatives to protect children from potential harms and to include their perspectives

in matters that impact their lives (Broddy, 2014; Redmond, 2003; Woodgate et al., 2017). Some groups argue that because young people do not have socio-cultural power, cognitive capacity, or sufficient information and life experiences, adults must protect them from risks associated with research participation. Others argue that withholding children's right to contribute to knowledge that impacts their lives renders them invisible, voiceless, and therefore more powerless (Markowska-Manista, 2021). Fecke et al. (2022) claim that by excluding children from empirical research we also deny them the opportunity to benefit from the results of research. In the social sciences not only are data gathered from children rare, but data about children are also missing from important data sets. In Europe and Canada, for instance, the national census excludes children below the age of 15 years. Statistical information about them is either estimated, or compiled from other sources, but projections based on these data lack the credibility of census data.

Loveridge et al. (2024) point out that although research with children and youth has recently become more participatory and inclusive, there is little institutional guidance on ethical issues associated with this work. They recommend taking a feminist ethic of care approach, which is contextually contingent, responsive, and responsible. Complex inter-relational dynamics are a part of this work and require "holding open ethical space" (Loveridge et al., 2024, p.19), within which roles are negotiated. This approach encourages mutual respect and reciprocity, rather than a relationship of dependency between researchers and children and youth.

Refugee children and youth are considered particularly vulnerable because they are assumed to have witnessed violence, injury, and death, or learned about it from friends and relatives (see Ali, 2021). They may have lost parents who normally protected them, or trust in their ability to protect them in the face of their own fear and helplessness. Many organizations and individuals become involved in their protection, acquiring the status of formal and informal gatekeepers. Some of these have their own hierarchical structures and conflicting loyalties (see Fecke et al., 2022) that impact who can or cannot have access to the children and youth.

As noted above, North American academics first must seek approval from their universities' REBs to conduct research. To approach children (usually defined as persons below the age of 18 years) they are required to first obtain consent from parents or legal guardians. Some REBs ask researchers to submit assent forms in a simplified form of the children's native language; explain how they will be protected from parental coercion to participate in a study or not; and describe in detail how their privacy will be ensured. However, researchers can sometimes convince REBs to modify their requirements. Ali and Gibran (2020) sought permission to interview Syrian refugee children in their homes, where other family members could see and hear them, claiming that the family's sense of security was a higher priority than the privacy of the child. They argued that refugees who had recently arrived in Canada after several years in a third transition country, with little or no experience of engaging with researchers, were likely to feel more secure witnessing their child's interactions with a researcher than sending them off to a private space with a researcher. The REB agreed and granted approval.

Gatekeepers in places where children and youth congregate, such as schools or community centres, can be wary of letting researchers into their space. Fecke et al., (2022) point out that there are often a series of people, rather than a single person who control researchers' access to children and youth. Those who work with them, such as teachers, coaches, or counsellors, may not want children and youth in their care to skip their 'regular' tasks to generate data for researchers. They may also have privacy concerns related to the children and youth, themselves or their organization; or doubt the validity or usefulness of the study (Fecke et al., 2022).

Parents or guardians may similarly be wary of letting children and youth in their care talk to researchers. They may be concerned that children may reveal information the family does not want to share, such as having applied for asylum in another country, which could put their precarious legal status at risk. Meloni et al. (2015) also suggest that children who are dependent

on adults may hide information they think their families would not like to be shared. To illustrate this point, they give the example of a teenage refugee girl who fell silent rather than contradict her parent about her adjustment experience in their new location. Furthermore, refugee children and youth may hide information they think adults on whom they depend on may disapprove of, such as gang membership, use of alcohol and illicit drugs, or sexual activity (see Leadbeater et al., 2006). Unaccompanied minors are a particularly vulnerable sub-group of refugee children and youth. Understanding their perspectives is critically important to offer them appropriate support, but adult gatekeeping makes it very difficult to recruit them for research (see Vervliet et al., 2015). Researchers may be put off by additional challenges in navigating multiple formal and informal gatekeeping procedures by institutions as well as parents or guardians in order to work with children (Fecke et al., 2022).

Significant differences between researchers and refugee children and youth present additional challenges in effective communication. Children with whom researchers do not share conceptual knowledge and life experiences, or a common language and culture, can be difficult to engage (Adler et al., 2019; Boddy, 2014; Wihstutz, 2020). In the literature we could access, we did not find any account written by a researcher who had sought refuge in ways similar to those of the children they were studying. Most researchers have little or no experience in working with children in other contexts either. Their age difference, in and of itself, can make it difficult for researchers to collect useful data. However, as Wihstutz (2020) shows in an ethnographic study, observation and non-verbal communication with young refugee children, along with research conversations with their parents and caregivers, can offer useful glimpses into their lives.

Boddy (2014) points out that concepts and vocabularies related to race, ethnicity, social class, and cultural and national origins are complex, dynamic, and context dependent. Researchers have to keep in mind that refugee children and youth may ascribe to them identity markers that shape how they interact with them. Most displaced people currently come from countries that were colonized by Europeans. Older refugee children and youth are often aware of 'White people's' historical occupation of their country, their current socio-political status, and their power to make decisions that affect the children's and their families' lives. Researchers who are associated with racial/ethnic identities, or nationalities and institutions that are presumed to hold power, are seen as resources to be drawn upon for attention, information, advocacy, and sometimes even money (Bilotta, 2020; Erden-Basaran, 2021; Vervliet et al., 2015). Bilotta (2020) notes that refugee children and youth can have expectations from researchers, which they sometimes interpret as 'promises,' and feel deeply disappointed when they are not met. Writing about her work with a few Syrian refugee children in Turkey, Erden-Basaran (2021) claims that neither universities nor governments provide guidance on how to address refugee children's unrealistic expectations from researchers or unsustainable attachment to them. She suggests that researchers should plan individualized exit strategies after fieldwork to minimize emotional harm to the children. Vervliet et al. (2015) also suggest that regardless of whether such emotional challenges arise from miscommunication or misperceptions, researchers need to critically examine the purposes of their studies as well as their conduct as researcher. They claim that the emotional toll of managing explicit requests for help; of advocating for the children and families at multiple levels; and of juggling their own priorities and multiple, sometimes conflicting loyalties can become overwhelming.

Given the complex ethical issues associated with research that engages refugee children and youth, researchers may be tempted to avoid it. However, ethical researchers cannot simply turn away from ethically challenging work. Instead, they can try to disentangle some threads of a complex issue to gradually address the problem. In the following section, various dimensions of ethical issues in research with refugee children and youth are discussed to help manage this work.

Dimensions of Ethical Issues

Ethical issues in research are traditionally categorized as procedural, practical, or relational (Arendt, 1987; Block et al., 2011; Guillemin & Gillam, 2004,). These refer to methodological procedures planned by researchers that are sometimes subject to approval by a research institution; the application of these procedures in the field; and relationships with research participants and gatekeepers to research sites. Although the application of research procedures shapes and is shaped by research relationships, there is little in the current literature about relational ethics, especially in contexts where multiple and complex research relationships have to be navigated. Also missing from the literature are ethical concerns about data analysis and dissemination of findings, which raise significant challenges for researchers.

Procedural Ethics

As noted above, research regulations were developed in Western countries in reaction to the devastating consequences of biomedical and behavioural research in Europe. Current regulations in Canada are based on a convergence of opinions about ethically appropriate research procedures. Each of the three national research councils – Canadian Institute of Health Research (CIHR), Natural Sciences and Engineering Research Council (NCERC), and Social Sciences and Humanities Research Council (SSHRC) - have developed procedural guidelines which all researchers funded by the federal government through these councils have to follow. However, the guidelines are interpreted and enforced by institutional REBs of universities and other publicly funded organizations, who must approve research proposals before data collection can begin. The level of detail asked for by some of these makes it extraordinarily cumbersome and expensive, especially for researchers who work with participants who use different languages, may be illiterate, or are considered 'vulnerable' due to their uncertain legal status and age (Clark-Kazak, 2017). This author's university REB, for example, requires her to submit translations of consent and assent forms – and sometimes back translate to ensure accuracy – but also verbatim scripts of recruitment flyers, as well as telephone and e-mail recruitment invitations, in all languages used by her respondents. For a study involving children from Syria who had arrived as refugees, Ali and Gibran (2020) had to make the case multiple times to their REB for why they must talk to the children rather than just their parents, engage with them in their homes, and offer the parents an honorarium.

Some scholars (e.g. Kuakko, et al., 2017; Tilley, 2016) claim that university REBs make it unnecessarily difficult for researchers, especially those who undertake qualitative studies with refugee populations, to obtain REB approvals. They suggest that academics whose exposure to this approach is limited because of their disciplinary backgrounds, or prior research training and experience, can be suspicious of procedural integrity of qualitative studies because of their intrinsic lack precision and predictability.

Refugees' movements are both speedy and unpredictable, which means researchers cannot wait for delays in institutional approvals of procedural processes. However, research with refugees is often undertaken in the context of program evaluation, which makes is possible to be exempted from institutional approvals.

The speed at which methodological innovations are now created also complicates procedural ethics and their approvals. For example, technological advances have now made it much easier to collect visual data, data from social and other media, as well as large data sets from multiple sources. These are generated in opportunity-driven ways, not amenable to prediction or control by researchers.

Practical Ethics

Procedural ethics have to be interpreted and applied within specific situations, which Guillemin and Gillam (2004) refer to as practical ethics. In the project mentioned above, Ali and Gibran (2020) found that they had to rely on their understanding of 'situated ethics' (Ebrahim, 2010) in response to unexpected moves by the children or their parents during data collection. Two research assistants had been hired particularly for their fluency in English and spoken Arabic. They introduced themselves and the project in Arabic to the children and families. To make them comfortable, the lead research assistant also mentioned that she had trained and worked as a teacher – a role they were familiar with – including in refugee camps. She fully expected to interview the children in Arabic, their common first language. However, her past role as teacher prompted the children to speak with her in English – the language they used with their current teachers – which was also encouraged by some parents for the 'additional practice.'

Research assistants in the above study let parents observe their children's interviews but asked them not to interject during the conversations. Nevertheless, some parents asked their children to talk about specific incidents that were not necessarily important to the latter; others wanted to draw the researchers' attention to their own narratives; and all plied the researchers with snacks and drinks. While the procedures approved in the ethics application were followed, unexpected situations emerged throughout data collection, where the researchers had to rely on their presumed intent of procedural ethics. The team's experiential knowledge of having worked with children in a refugee camp, engagement with some Syrian refugee families in Canada, and familiarity with the Arabic language and culture, helped to make such 'on the spot' practical decisions.

Relational Ethics

As noted above, REBs typically provide very specific instructions about procedural steps in collecting data from human subjects but are often silent on research relationships. This may be due to the assumption that procedural steps will ensure the ethical integrity of research relationships. However, researchers interpret procedural steps in ways that help them collect the best data they can but also get socio-emotionally involved in human subjects of their study. Some may express their understanding and empathy, but others think it is important to be distant and neutral. Researchers may advocate for their research participants, perform tasks such as filling a form, or bring them small gifts as a token of gratitude. A few build relationships that last beyond their research related engagement. In most cases, however, researchers struggle to maintain a balance between relationships that seem extractive, or overly demanding of time, energy and other resources.

Researchers create knowledge about people who participate in their projects. This action in and of itself creates a power imbalance between the two (Arendt, 1987). When they work with refugees, who have lost much of what they had, the imbalance is amplified. In many instances, refugees associate researchers with power and privilege that comes with economic affluence, socio-political connections, and cultural knowledge. Refugees assume researchers have access to what they need, such as social networks, financial resources, and the ability to negotiate with others on their behalf (Bose, 2020). These expectations raise ethical issues for researchers. They may want to help the refugees out of compassion, but this may also feel like an 'exchange' for data. The boundaries of professional and personal relationships become murky in such situations. It is important to keep in mind that researchers' own cultural and academic backgrounds also influence their decisions. For example, hugging a distressed participant to convey empathy may feel very 'natural' to some researchers but to others it may feel like crossing the boundary of a professional relationship.

Refugees also have culturally-based relational norms that are new to some researchers. For a study with government and privately sponsored Syrian refugees, Ali et al. (2021) first interviewed them as couples and then in gender-segregated groups. During the interviews with couples, regardless of the researcher's gender, many of the men spoke on behalf of the women – who merely agreed with their husbands – leaving the researchers unsure about how far to insist on hearing from the women directly. They wondered if building a relationship with one member of a family would jeopardize their relationship with the other. Should an ethical research relationship be construed on the basis of researchers' conceptions of gender equity, or was it more important to respect the respondents' views about gender roles within their family?

In research with refugee children, youth, and families, the use of interpreters and cultural brokers is fairly common. However, interpreters are selected on the basis of their familiarity with languages and cultures of both parties and mediate their communication in ways that are not transparent to either. Maintaining a trusting relationship with them while ensuring that they adhere to what exactly is communicated by either party is another difficult balancing act. Similarly, gatekeepers of organizations that provide access to refugee children, youth, and families can exercise power in choosing which people researchers can talk to and under what conditions. How do we work with the various gatekeepers to gain access to research participants we want to include and to hear what they want to tell us?

Developing and maintaining ethical relationships with individual research participants is difficult enough. In research with refugees many other stakeholders are also involved. If the research participants are children, their families or guardians also must be considered. Some of these relationships may conflict, or compete with others for priority, which makes ethical navigation of these relationships a difficult task.

Analytical Ethics

Researchers generate knowledge that can have a profound impact on the lives of refugee children, youth, and families. It is important to remember that their knowledge claims are based on prior theories, the literature consulted, the data gathered, and the purposes, audiences, and contexts of their studies. Published works often treat analyses as 'techniques' that establish the 'truth value' of researchers' claims. However, the ethical dimension of analytical processes is hardly ever discussed in the literature.

Analytical strategies used for meaning-making are based on a common language, culture. communicative norms, and conceptual categories. They do not necessarily work well in situations where there are many social, political, economic, ideological, and experiential differences between researchers and research participants. For example, in many parts of world the notion of 'honour' is critical to survival and transgressions against it have led to loss of human life (Nowak et al., 2016). Meanings associated with this term, however, evolve differently in different contexts. Researchers who are unfamiliar with how their research participants interpret the term may misunderstand the latter, even when they use a translated version of the word. This problem is exacerbated in quantitative research where reduction of meaning is unavoidable. Even in qualitative studies, researchers may assign different meanings or significance to some of their participants' responses and fail to understand or appreciate others because of the differences noted above. In the Western world, for example, age is a very important determinant of legal status and its related prohibitions, protections, and privileges, but in countries that refugees often come from, age is not necessarily known or formally recorded. Furthermore, refugees may choose not to disclose information being sought by researchers or falsify it because of their hypervulnerability. Some methodologists suggest verification of data collected through memberchecking or asking others familiar with the respondents' situation and their language/culture.

However, refugees may not stay long enough in one place for researchers to verify their analyses or ask others who may share their cultural and experiential backgrounds.

Other factors further complicate this process. Because communication between refugee families and researchers often happens through interpreters, another layer of uncertainty is added between what was intended and understood. The context in which the interactions take place can also distort the participants' responses and the researchers' perceptions about them. Writing about three Syrian refugee children, Erden-Basaran (2021) claims that their lack of secure attachments to traumatized parents, and dependence on multiple transient 'caregivers,' led to an 'excessive' attachment to her during fieldwork in a Turkish refugee settlement. It seems that the context of her engagement with these children, combined with a Western theoretical orientation and expectations regarding researchers' roles and relationships, led to this conclusion. Given that data from parents or other caregivers were not included in the analysis, this conclusion seems unwarranted and runs the risk of positioning the children and their families as deviant and deficient others (see Bühler-Niederberger, 2011).

Children sometimes 'embellish' their data in ways that researchers may not fully understand. In Ali and Gibran's study (2020), some girls form Syria drew flowers on and around their houses in the transition country. When probed, they explained that they did not actually have flowers around their houses but had drawn them as they were 'decorating' their drawings. Talking about what surprised her upon arrival in Toronto, a child said she saw people who were white, black, brown and 'turquoise!' Our guess is that she was using this word playfully, which children sometimes do with newly learned words, but we will never know for sure. Examples such as the above illustrate idiosyncrasies of children's expressions, but also the limits of our ability to understand what they want to communicate.

An ethical approach to the analysis of data generated by refugee children, youth, and families requires researchers to reflect on our analytical processes (see Schön, 1987) and explicitly acknowledge the limits of our knowledge.

Ethics in Dissemination

Researchers obviously want to widely disseminate what they learn from their studies. The organizations that fund this research also want the work to garner public attention, partly to influence decision-makers, but also to showcase their research. However, dissemination of research with refugee children, youth, and families has some ethical dimensions that other kinds of research may not.

Refugees are vulnerable in ways that legal residents and citizens of a country are not. They may not fully understand the limits of protection being offered regarding confidentiality. They may 'choose' to participate in studies, but their financial situation, loneliness, and sense of helplessness in an unfamiliar environment may not make this a real choice. Simply being recognized by state authorities may signal their potential association with criminality (see Kaukko et al., 2017), lead to deportation, or being asked to provide evidence against others. In short, researchers' desire to advocate for refugees by disseminating knowledge about them may actually have negative consequences for them.

Dissemination of findings related to the evaluation of projects and programs for refugee protection or resettlement have additional challenges. Standard precautions taken to prevent the identification of programs or their personnel are simply insufficient because there are only a few such programs in any given context. Those directly involved in such programs may recognize refugee participants, even if they are not named. Programs designed to serve refugees may be limited by human and material resources that researchers are not necessarily aware of. Their intent may be to help improve a program, but they may inadvertently jeopardize its funding or put

its employees' jobs at risk. Public dissemination of evaluation studies is thus also fraught with ethical dilemmas.

Conclusion

Scholars that are considering research with refugees are strongly encouraged to undertake this work. Refugee children, youth, and families are highly vulnerable members of our society, trying to survive in an alien environment where their prior skills, strategies, and networks no longer serve them. They arrive with few material belongings, or social and political resources, and depend heavily on people who do not know their language, culture, or experiences. To begin with, very few researchers in the Global North have had similar experiences or learned about them from family members or close friends. Because refugee children, youth, and families' experiences are so unfamiliar, only a few researchers are sufficiently invested in studying their issues. Second, collecting data from them is difficult because of multiple institutional and individual gatekeepers, who may have conflicts of interest in facilitating researchers' access to them. Third, researchers' unfamiliarity with languages and cultural habits of refugees greatly increases the space for insufficient or incorrect understandings of what they communicate. Fourth, researchers can inadvertently put refugee families at risk because they may not fully appreciate the legal and political contexts in which they engage with their respondents. And finally, complex ethical issues based on real and perceived power difference between researchers and respondents may dissuade researchers from undertaking such work. However, the risk of not doing research with refugee children, youth, and families is even higher. Excluding them from debates and discussions that impact them the most is simply unethical. Ethical researchers must take the responsibility of doing such research, despite its many challenges.

References

- Ali, M. A. (2021). Syria was once a Beautiful Country [Video]. Vimeo. https://vimeo.com/503310840
- Ali, M. A., & Gibran, G. (2020). Documenting Syrian refugee children's memories: Methodological insights and further questions. *International Journal of Qualitative Methods*, *19*, 1609406920938958. https://doi.org/10.1177/1609406920938958
- Ali, M. A., Zendo, S., & Somers, S. (2022). Structures and strategies for social integration: Privately sponsored and government assisted refugees. *Journal of Immigrant & Refugee Studies*, 20(4), 473–485. https://doi.org/10.1080/15562948.2021.1938332
- Arendt. (1987). Labor, Work, Action. In S. J. J. W. Bernauer (Ed.), *Amor Mundi* (Boston College Studies in Philosophy, Vol. 26, pp. 29–42). Springer. https://doi.org/10.1007/978-94-009-3565-5 2
- Bilotta, N. (2021). A critical self-reflexive account of a privileged researcher in a complicated setting: Kakuma refugee camp. *Research Ethics Review*, *17*(4), 435–447. https://doi.org/10.1177/17470161211037386
- Block, K., Warr, D., Gibbs, L., & Riggs, E. (2013). Addressing ethical and methodological challenges in research with refugee-background young people: Reflections from the field. *Journal of Refugee Studies*, *26*(1), 69–87. https://doi.org/10.1093/jrs/fes002
- Bloemraad, I., & Menjívar, C. (2022). Precarious times, professional tensions: The ethics of migration research and the drive for scientific accountability. *The International Migration Review*, *56*(1), 4–32. https://doi.org/10.1177/01979183211014455
- Boddy, J. (2014). Research across cultures, within countries: Hidden ethics tensions in research with children and families? *Progress in Development Studies*, *14*(1), 91–103. https://doi.org/10.1177/1464993413490477
- Bose, P. S. (2022). Refugee research in the shadow of fear. *GeoJournal*, 87(Suppl 2), 195–207. https://doi.org/10.1007/s10708-020-10342-w
- Chatzipanagiotidou, E., & Murphy. (2022). Exhibiting displacement: refugee art, methodological dubiety, and the responsibility (not) to document loss. In K. Grabska & C. R. Clark-Kazak (Eds.), *Documenting displacement: Questioning methodological boundaries in forced migration research* (Vol. 7, pp. 81–103). McGill-Queen's University Press. https://doi.org/10.1515/9780228009498-006
- Clark, J., & Richards, S. (2017). The cherished conceits of research with children: Does seeking the agentic voice of the child through participatory methods deliver what it promises?. In Researching children and youth: Methodological issues, strategies, and innovations ((Vol. 22, pp. 127–147). Emerald publishing limited. https://doi.org/10.1108/S1537-466120180000022007
- Clark-Kazak, C. (2017). Ethical considerations: Research with people in situations of forced migration. *Refuge*, *33*(2), 11–17. https://doi.org/10.7202/1043059ar
- Clark-Kazak, C. (2019). Developing ethical guidelines for research. *Forced Migration Review*, (61), 12-13. https://doi.org/10.1177/23315024211034401
- Clark-Kazak, C. (2021). Ethics in forced migration research: Taking stock and potential ways forward. *Journal on Migration and Human Security*, 9(3), 125–138. https://doi.org/10.1177/23315024211034401
- Ebrahim, H. B. (2010). Situated ethics: Possibilities for young children as research participants in the South African context. *Early Child Development and Care*, *180*(3), 289–298. https://doi.org/10.1080/03004430701822958
- Erden-Basaran, O. (2021). Protecting refugee students' wellbeing after research. *International Journal of Qualitative Methods*, *20*, 160940692110258. https://doi.org/10.1177/16094069211025892
- Farr, G. M. (Ed.). (2020). Afghan resistance: The politics of survival. Routledge.

- Fecke, M., Fehr, A., Schlutz, D., & Zillich, A. F. (2022). The ethics of gatekeeping: How guarding access influences digital child and youth research. *Media and Communication*, *10*(1), 361–370. https://doi.org/10.17645/mac.v10i1.4756
- Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings, 1972-1977.* Vintage.
- Gilligan, C. (1993). *In a different voice: Psychological theory and women's development.*Harvard University Press.
- Government of Canada. (2020). #WelcomeRefugees: Key figures. Immigration and Citizenship. Retrieved from https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/welcome-syrian-refugees/key-figures.html
- Grabska, K., & Clark-Kazak, C. R. (Eds.). (2022). *Documenting displacement: Questioning methodological boundaries in forced migration research* (Vol. 7). McGill-Queen's University Press.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative inquiry*, 10(2), 261-280. https://doi.org/10.1177/1077800403262360
- Israel, M. (2015). Research ethics and integrity for social scientists: Beyond regulatory compliance. Sage.
- Kant, I. (2017). *The Metaphysics of morals* (L. Denis, Ed.; M. Gregor, Trans.; 2nd ed.). Cambridge University Press. https://doi.org/10.1017/9781316091388
- Karooma, C. (2019). Research fatigue among Rwandan refugees in Uganda. *Forced Migration Review*, *61*, 18-19.
- Kaukko, M., Dunwoodie, K., & Riggs, E. (2017). Rethinking the ethical and methodological dimensions of research with refugee children. *ZEP: Zeitschrift für internationale Bildungsforschung und Entwicklungspädagogik,* 40(1), 16-21. https://doi.org/10.25656/01:16924
- Kyriakides, C., Bajjali, L., McLuhan, A., & Anderson, K. (2018). Beyond refuge: Contested orientalism and persons of self-rescue. *Canadian Ethnic Studies*, *50*(2), 59-78. https://doi.org/10.1353/ces.2018.0015
- Landau, L. B. (2019). A chronotope of containment development: Europe's migrant crisis and Africa's reterritorialisation. *Antipode*, *51*(1), 169-186.https://doi.org/10.1111/anti.12420
- Leadbeater, B. J. R., Bannister, E., Benoit, C., Marshall, A., Jansson, M., & Riecken, T. (Eds.). (2006). *Ethical issues in community-based research with children and youth*. University of Toronto Press.
- Loveridge, J., Wood, B. E., Davis-Rae, E., & McRae, H. (2024). Ethical challenges in participatory research with children and youth. *Qualitative Research*, *24*(2), 391-411. https://doi.org/10.1177/14687941221149594
- Macfarlane, B. (2010). Researching with integrity: The ethics of academic enquiry. Routledge. Markowska-Manista, U. (2021). Research "about" and "with" children from diverse cultural
 - backgrounds in Poland–dilemmas and ethical challenges. *Edukacja Międzykulturowa,* 14(1), 233-244. https://doi.org/ 10.15804/em.2021.01.14
- McFarlane, C. (2010). The comparative city: Knowledge, learning, urbanism. *International journal of urban and regional research*, *34*(4), 725-742. https://doi.org/10.1111/j.1468-2427.2010.00917.x
- Meloni, F., Vanthuyne, K., & Rousseau, C. (2015). Towards a relational ethics: Rethinking ethics, agency and dependency in research with children and youth. *Anthropological Theory*, *15*(1), 106-123. https://doi.org/10.1177/1463499614565945
- Müller-Funk, L. (2021). Research with refugees in fragile political contexts: How ethical reflections impact methodological choices. *Journal of Refugee Studies, 34*(2), 2308-2332. https://doi.org/10.1093/jrs/feaa013
- Noddings, N. (2003). Happiness and education. Cambridge University Press.

- Nowak, A., Gelfand, M. J., Borkowski, W., Cohen, D., & Hernandez, I. (2016). The evolutionary basis of honor cultures. *Psychological science*, *27*(1), 12-24. https://doi.org/10.1177/0956797615602860
- Perry-Hazan, L. (2016). Children's participation in national policymaking: "You're so adorable, adorable, adorable! I'm speechless; so much fun!". *Children and Youth Services Review,* 67, 105-113. https://doi.org/10.1016/i.childyouth.2016.05.015
- Piccio, D. R. (2016). "United in diversity": research ethics in European political science. *Political Science & Politics*, 49(4), 839-844. https://doi.org/10.1017/S1049096516001542
- Rawls, J. (1993). *Political liberalism.* Columbia University Press.
- Redmond, M. (2003). Cultural and ethical challenges in cross-national research: Reflections on a European Union study on child & youth migration. *International Journal of Qualitative Methods*, *2*(4), 15-24. https://doi.org/10.1177/160940690300200402
- Resnik, D. B. (2012). Ethical virtues in scientific research. *Accountability in research*, 19(6), 329-343. https://doi.org/10.1080/08989621.2012.728908
- Schön, D. A. (1983). The reflective practitioner: How professionals think in action. Basic Books.
- Schön, D. A. (1987). Educating the reflective practitioner: Toward a new design for teaching and learning in the professions. Jossey-Bass.
- Taylor, C. (1992). Sources of the self: The making of the modern identity. Harvard University Press.
- Thacher, D. (2004). The casuistical turn in planning ethics: Lessons from law and medicine. Journal of Planning Education and Research, 23(3), 269-285. https://doi.org/10.1177/0739456X03261286
- Tikly L. & Bond, T. 2013. Towards a postcolonial research ethic in comparative and international education. *Compare: A Journal of Comparative and International Education, 43* (4) 422-442. https://doi.org/10.1080/03057925.2013.797721
- Tilley S. A. (2016). *Doing respectful research: Power, privilege and passion.* Fernwood Publishing.
- Vervliet, M., Rousseau, C., Broekaert, E., & Derluyn, I. (2015). Multilayered ethics in research involving unaccompanied refugee minors. *Journal of Refugee Studies*, *28*(4), 468-485. https://doi.org/10.1093/jrs/feu039
- von Unger, H., Dilger, H., & Schönhuth, M. (2016). Ethics reviews in the social and cultural sciences? A sociological and anthropological contribution to the debate. *Forum, Social Research*, *17*(3). https://doi.org/10.17169/fgs-17.3.2719
- Wihstutz, A. (2020). 'I can't sit here and cry with you, I have to play'. Strategies by very young children in refugee collective accommodation. *European Early Childhood Education Research Journal*, 28(1), 115-128. https://doi.org/10.1080/1350293X.2020.1707367
- Woodgate, R. L., Tennent, P., & Zurba, M. (2017). Navigating ethical challenges in qualitative research with children and youth through sustaining mindful presence. *International Journal of Qualitative Methods*, *16*(1), 1609406917696743. https://doi.org/10.1177/1609406917696743