Longitudinal Community-based Research with refugees:

Ethical Challenges Faced by Peer Researchers

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Centre for Refugee Studies

Funded by:
CIHR IRSC

This fact sheet was developed based on a recent book chapter written by the SyRIA.lth team: *"Oda, Anna, Adnan Al Mhamied, Riham Al-Saadi, Neil Arya, Mona Awwad, Oula Hajjar, Jill Hanley, Michaela Hynie, Nicole Ives, Rabih Jamil, Mahi Khalaf, Rim Khyar, Ben C. H. Kuo, May Massijeh, Rana Mohammad and Kathy Sherrell. Ethical challenges of conducting longitudinal community-based research with refugees: Reflections from peer researchers. In K. Grabska &C. Clark-Kazak (Eds.). In press. Research Methods in Forced Migration. McGill-Queens University Press."* It provides a reflection on the ethical challenges peer researchers experienced while working on longitudinal mixed-method community-based research study looking at the integration and long-term health outcomes of Syrian refugees resettled in Canada (SyRIA.lth). The purpose of this fact sheet is to act as a resource for those who are working with peer researchers on community-based research (CBR).

This fact sheet will provide an overview on:
Four key ethical issues peer researchers encountered during the project:
Ethical challenge #1: Positionality and the insider/outsider position
Ethical challenge#2: Professional role conflict
Ethical challenge #3: Compassion fatigue and burnout
Ethical challenge #4: Distress and secondary trauma
Recommended strategies implemented by project team to support peer researchers.

About Refugee Integration and Long-term Health Outcomes in Canada (SyRIA.lth) project:

SyRIA.lth is a community-based pan-Canadian longitudinal study funded by The Canadian Institute of Health Research (CIHR) and housed in the Centre for Refugee Studies (CRS), York University. The project is a partnership between settlement service agencies and academic research institutions in three of Canada's largest refugee resettlement provinces: British Columbia, Ontario, and Quebec. It is looking at how different resettlement programs support the social integration of Government Assisted Refugees (GARs) and Privately Sponsored Refugees (PSRs) and the impact of integration pathways on their long-term physical and mental health.

The goal of this project is to produce knowledge that will:

1. Inform promising practices for refugee resettlement and integration
2. Strengthen knowledge exchange in the settlement sector
3. Identify the impact of settlement policies on refugee health and well-being
4. Deepen our understanding of the influence of social conditions on long-term health and well-being

Theoretical underpinning:
This project is guided by the Holistic Integration Model (HIM) developed. This model looks at integration from multiple different aspects including social (i.e. social connections, community welcome), interactional (i.e. language, employment) and subjective (i.e. sense of belonging).

Arabic-speaking peer researchers including those who were Syrian refugees themselves, recent Syrian immigrants, second generation Syrian Canadians or immigrants from other Middle Eastern countries were hired to conduct:

- Interviews once a year for four years since 2017 with newly arrived Syrian refugee adults
- Focus groups to gain more insight into the nature of people's experiences

For more information, visit SyRIA.lth website: http://syrialth.apps01.yorku.ca/

Section A: Four key ethical issues peer researchers encountered during the project:

Ethical challenge #1: Positionality and the insider/outsider position

Identifying communities and identifying oneself as a "member" of a certain community can be very complex. Members of the same community often have different demographic and socioeconomic characteristics, as well as different religions, histories and political views. The latter is a particularly important issue in communities that have experienced conflict. Thus, despite their shared language and/or nationality, which initially classified peer researchers as insiders of the Syrian refugee community, there could be considerable social distance between them and research participants.

Due to this social distance, peer researchers perceived themselves as outsiders, which could lead to feelings of discomfort and distress during interviews:

> *"I knew that when I enter participants' houses, they would consider I am on the neutral side and that they won't try to open with me any political conversations. However, I had to listen many times to some political opinions that the participants shared with me and I personally totally disagree with, but I had just to listen and nod my head and try to pass to the next questions. That didn't feel easy all the time."*

The privileged researcher role also often made peer researchers feel outside of the community, because of their more powerful position and the fact that they represented the research project, but also because peer researchers were trained on how to establish professional boundaries during the research study, which entailed distancing themselves from the community.

This inherent power imbalance between peer researchers and participants sometimes created tension and challenged trust. Thus, the insider/outsider roles not only impacted the mental well-being of peer researchers, but it also impacted relationship dynamics:

> *"When we told them about the consent forms' signature, they often would tell us stories about them being tricked by someone to sign something here in Canada."*

The longitudinal aspect of the study facilitated trust building between peer researchers and participants, enhancing the quality of the data. This was especially true if the interviews were conducted with the same peer researcher every year. However, it complicated and challenged necessary professional boundaries:

> *"Conducting the interviews for 3 years in a row with some families made the participants feel more comfortable with the questions and the research process. They felt more comfortable to ask more questions about existing resources and express their opinion about their current life and well-being."*

> *"I often meet participants in public places such as the mall or grocery store. For confidentiality reasons, I know that it is better not to talk too much to them, but it was challenging to do so tactfully, especially because the study is longitudinal."*

Ethical challenge#2: **Professional role conflict**

The second challenge peer researchers faced was related to conflict between their different professional roles. Many simultaneously worked as settlement or social workers, professional interpreters, and psychologists. These peer researchers reported challenges related to distancing oneself from the primary service provider role during research, especially with Syrian refugees who could benefit from services:

> *“Some of the young adults interviewed would ask me about college applications and acceptance. I try to answer their questions with the knowledge that I have and within reason. Keeping the relationship to strictly research was also tough for me.”*

The research team was directed to avoid providing services because the study was intervention research, many peer researchers were not qualified to provide the needed support and so might cause more harm than good, and the team wanted to avoid coercion; participants can feel they need to participate in order to receive services. Peer researchers working in service provision fields such as social work, however, argued that researchers have the ethical obligation of not only doing no harm but also of doing good, and that performing small courtesies is part of the ethical obligation. Identifying the boundaries of these actions was challenging

Ethical challenge #3: **Compassion fatigue and burnout**

Compassion fatigue is strongly linked to the aspect of professional role conflict peer researchers faced. Compassion fatigue can be identified as the stress resulting from wanting to help those who are suffering and in need, beyond one’s abilities:

> *“The highest level of compassion fatigue was triggered by the issues that, even as a settlement worker, I have no solutions, such as the language barrier, especially for elders who cannot learn a language easily. One participant described his feelings about this issue as “being deaf”; he said this is how he feels in Canada with a very painful tone, as if he actually lost his voice and sense of hearing. Another common problem without any solution is family reunification, which to some people is the only solution to their sorrows.”*

When it is not addressed and managed in time, compassion fatigue can lead to further complications and even to professional burnout.

Ethical challenge #4: **Distress and secondary trauma**

One of the most valuable things peer researchers and participants identified was the opportunity to share and listen. It felt very rewarding to both peer researchers and participants. Many participants shared their feelings of gratitude for having someone to listen to their stories, especially those participants who experienced isolation:

> *"Working as a researcher with people – I consider myself to belong to them – was enjoyable. Through this work I was not only able to enter their places, they opened their hearts to me. Many times, I left, elderly women hugging me. During Ramadan, people (especially Christians) gave me candies, some of them offered to me to break my fast with them. Even though it was painful to listen to stories from elderly people, it was a pleasant moment for me to close my iPad and listen to women who are struggling from isolation and they want someone to listen. A lady told me once 'You are the first one to knock on our door in a week.'"*

On the one hand, it was sometimes difficult and draining being present and actively listening to participants and their stories. Many Syrian refugees faced hardships and traumatic life events during their migration journey, which some shared with peer researchers. The nature of the face-to-face interview process created opportunities for additional disclosures and almost all participants chose to share additional information that was not part of the survey. Some of this information was distressing:

> *"When participants recalled their difficult migration stories and the losses they experienced, I found myself involved and cried as she was crying. I let her finish her story and then I asked for a break for both of us before we could continue the survey. This situation was very difficult."*

Secondary trauma, also known as vicarious trauma, can occur as a result of working with trauma survivors and listening to their stories. Peer researchers can become traumatized themselves and experience symptoms similar to post-traumatic stress disorder (PTSD) after such encounters:

> *"I think what I found to be most challenging part to me throughout the process was listening to the stories. Most of the time, participants were willing to share their personal stories with us, some of which are remarkably painful. I would listen to these stories and try to absorb their frustration and sorrow. I remember in one interview, I ended up crying with my participant and feeling down about their story the entire week. It is in those moments I think that it gets complicated to separate your researcher self from your human and Syrian self."*

Section B: Recommended strategies implemented by project team to support peer researchers:

If researchers are to conduct ethically-sound research, there is a need to address peer researchers' involvement in CBR with vulnerable communities. The ethical obligation of minimizing the risk of harm applies not only to participants, but also to peer researchers, who are themselves members of these communities.

To support peer researchers, this project implemented multiple strategies. These included:

- Peer researchers were trained prior to data collection every year. Training included instructions on how to establish professional boundaries and obtain informed consent.
- An online workshop around self-care was offered annually, led by a team member with expertise working with immigration officers around secondary trauma, compassion fatigue and self-care.
- Each site also had access to mental health resources for peer researchers, including individual team members with mental health expertise and information about additional resources available at their site.
- Regular individual and team meetings were scheduled with peer researchers at each site led by research coordinators and supervised closely by project investigators. These meetings served as a safe space where peer researchers were encouraged to share stories and reflect on their experiences. Discussion groups were also created on WhatsApp for additional informal support. Regular team meetings and on-going communication were particularly valuable as a mean for informal support:

> *"By having the team's support and our weekly meetings, it allowed me to share my feelings and thoughts, which helped me to deal with the uneasy task of listening to the participants' emotional stories."*

- Efforts were made to ensure that those peer researchers who worked in the settlement sector refrained from recruiting and interviewing clients at the settlement agencies they worked with. This strategy was useful in avoiding any possible coercion, conflict of interests or confusion around the study's purpose.
- In advance of conducting the study, each research site had developed resource handouts with contact information for different settlement agencies that participants could access for support in their communities.
- When peer researchers went to participants' home to conduct the interviews, they were encouraged to go in pairs. This strategy was important for ensuring the safety and well-being of peer researchers. It also facilitated informal support opportunities where peer researchers had a companion with whom to share emotional support:

> *"I was teamed up with another peer researcher through the work duration to facilitate the work, have a travel companion and assure our safety all the time."*

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