

Anticipating and Addressing Challenges Utilizing Patient Oriented Research

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Abstract

Background: Over the last decade, Canada's demographics and ethnic makeup have undergone significant changes with an influx of refugees from many different countries.

Problem: There is a need to improve resources and access to health care services to adequately meet the health needs of refugees.

Approach: Patient-Orientated Research is required to enhance all stakeholders' understanding the health status and healthcare needs of refugees and immigrants who have resettled in Canada.

Outcome: This article reflects our experience using methods to engage refugees as partners on our research team. We learned about the sensitivities, ideas, emotions and life experiences of the refugee community and how that intersect with patient-oriented research methods.

Conclusion: Researchers must be mindful and show respect, empathy, and acceptance to create a culturally appropriate and safe environment in research.

Keywords: Refugee, Research, Patient-Orientated, Community

Introduction

Canada is a multicultural country with a nation which strives to be welcoming and accepting of people from diverse ethnic and cultural backgrounds. Over the last decade, Canada's demographics and ethnic makeup have undergone significant changes with an influx of refugees from many different countries. The Interim Federal Health Program (IFHP) provides limited, temporary coverage of health care benefits for refugees [1]; however, nurses and other health care professionals find they need to advocate for resources to adequately meet the health needs of refugees. There is a lack of access to quality health services for refugees, including resources to improve the communication process between care providers and the refugee [2-4]. Refugees have physical and mental health needs, yet they face unique barriers and challenges with accessing health services in Canada [3].

One significant barrier to accessing necessary health services is the lack of culturally appropriate health care services. In order for Canada to establish and provide culturally appropriate care, more research must be conducted to better understand the health care needs of the refugee and immigrant communities across the country.

In turn, this can assist to effectively address the gaps in the existing resources and health services. This type of research calls for the refugee and immigrant communities to be involved and engaged in the entire research process.

There is a desire and commitment for patient-oriented research in the health sector across Canada. Patient-oriented research is based on the premise that patients are research partners and are actively a part of the entire research process. This article reflects our experience engaging a refugee community from Saskatchewan, Canada as partners on our research team. The primary influence underpinning the research project was to gain an understanding of how the refugees' social networks affect their mental health and wellbeing. The team faced unique challenges related to the historical processes with grant funding, and the new context of patient-oriented research with a vulnerable refugee population. In this reflection we offer recommendations for other nurse educators embarking on patient-oriented research with refugee and immigrant populations.

Patient Orientated Research

Patient-oriented research can be described as research where patients are engaged as active partners in the process [5]. The term patient in patient-oriented research can refer to an individual, family,

and community. Issues being explored in the patient-orientated research are identified as important by the patients and must intend to improve patient outcomes [6]. Having the patients involved in all aspects of the research process increases the likelihood that the research is applicable [5], and reflects their reality [7]. Patient involvement in research can improve the research by making the questions more relevant, refining data collection methods, and enriching data interpretation [7]. With patient-orientated research, the patients, researchers and practitioners work together from the beginning to identify problems and gaps, as well as working together to drive change with health care services that will benefit the patients [6]. It is essential to create safe environments that promote honest interactions, financial compensation, cultural competence, training, and education for the patients to collaborate on the project [6].

Our Patient-Oriented Research Multidisciplinary Team

Patient-orientated research not only requires the patient to be involved, it also requires a multidisciplinary team to move the research into action. Our multidisciplinary team included two representatives of the refugee community whom were former refugees to Saskatchewan and are now working with the resettlement program facilitating the transition process for new refugees. These two members operated as patient advisors on our project. The team also included a patient coordinator, an experienced researcher, a nurse educator who works with the community, and a registered community health nurse. The patient advisors and patient coordinator provided the nurse researcher with direction in forming the team, determining the research topic, the overall research process, and identifying potential community partners to move the project forward into action.

Grant Application Practices and Processes

As with all research project, our team set out to apply for funding. Grant applications commonly require co-applicants to submit a Curriculum Vitae (CV), which may include information about the applicant's webpage, presentations, publications, education, and employment. Part of the process often entails the co-applicants to create an electronic online account, which requires a computer or access to one, wifi/internet, and email. In addition to having a sophisticated competence using the Internet, basic reading and writing skills along with knowledge about creating documents, typing, and emailing. Submission of the CV and creating an online account allows the potential grant funder to verify the co-applicant's consent, and a summary of the applicant's knowledge and commitment to the anticipated research project. Involving patients in the grant application is meant to be empowering and inclusive [6]; however, our team identified unique indifferences that may arise when involving a vulnerable population of refugees in the process.

Unique Challenges when Involving Refugees in Research Grant Applications

Involving the patients in the grant application can build confidence and engagement [6]; however, with a vulnerable population there is the potential for a negative experience. Our team realized that it was essential to be cautious and maintain sensitivity when requesting refugee partners to share their work history, previous education and submit a CV. It is important to be attentive to the context of each research team member's situation as they may not have the resources, knowledge or skills to comply with the grant application requests. For example, we learned it was extremely difficult for some of our research team members to set up online accounts. The patient advisors helped us to gain insight about these sensitivities

and advocated for the community, revealing that refugees may feel offended, embarrassed, undignified, and frustrated. The refugee research partners can experience distrust when asked to identify past employment, education, training, and skills.

Relationships are at the heart of partnerships and it is important to recognize that refugees generally need additional time to develop trust as many have had negative, traumatic life experiences. For instance, many refugees have had experience with violence and war [8]. Exposure to interpersonal traumatic events, including torture, is associated with avoidant tendencies and distrust [9]. Refugees who suffer torture and war often are apprehensive about confidentiality and generally distrust organizations and governments [10].

Refugee partnerships in the research process require additional time as often there are language barriers, different understandings, enhanced stress, and various cultural beliefs, values, and worldviews that require creating a safe environment to have dialogue [8]. Language barriers and cultural differences can impact whether a team member feels included or respected. The language barriers can also generate obstacle for a person, such as difficulty understanding instructions with creating online accounts, operating computers, and using computer software. Difficulty with understanding what is requested is stressful. Applying for grant funding in itself is stressful, due to the competitiveness. Refugees are often already challenged with additional stress as a result of transitioning into a new culture. The challenges, disappointments, and extra work involved can overwhelm and cause too much undue stress for the refugees partnering in the research project.

Another significant consideration is the historical reality that applying for research funding and conducting research requires advance skills, knowledge and abilities. Traditionally research teams are evaluated on their experience and skills when applying for ethical approval and grant funding. Many refugees have not had the opportunity of attending any formal educational system or even working at a job to support themselves or their family. Many refugees experience difficulty gaining employment in their new country and over half of the refugees require social assistance [11]. As a result, refugee partners likely would not have had opportunities to accomplish grant funding co-applicant expectations; such as employment history, webpages, and presentations. Seeing incomplete sections on an application can make a person feel inadequate and excluded. Although working on the research team offers the refugee patient some form of reimbursement there are many other aspects to consider and to discuss with all members of the research team.

Overcoming the Obstacles

Our team worked collaboratively and assisted the refugee partners to complete the application process and create online CVs to promote an egalitarian relationship based on inclusion, and respect. Extra care and thoughtfulness was implemented to avoid generating feelings of inadequacy and exclusion with the refugee partners. Our group found it essential to obtain the proper permission and consent from managers, so the refugees did not fear they will get in trouble for participating in the study or joining the research team. We found it helpful to use key members of the community to help us gain access to and trust from the community.

Recommendations to Strengthen Research Partnerships with Refugees

Upon critical reflection, it became clear how important it is for the researchers to be mindful, sensitive, and take extra steps to empower and safeguard the refugee partner during the various stages of the research process. Specifically some essential actions for researchers to implement include taking time to truly build a relationship with the refugee community and research team members from the refugee community. It is also important for the researchers to work in close partnership with refugee community leaders, cultural advisors, settlement workers, and interpreters. Networking with the refugee community helps to build trust and enhance participation in the research project, which in turn will help ensure the research results are relevant [12]. Ultimately involving the refugee community as a true research partner helps to create change and bring a community together to influence community action.

At inception the research team should discuss the collaborative research partnership, plus address any differences in the understanding of the research process and the project goals/outcomes [13]. During all stages of the research process, researchers must nurture the refugees' sense of trust, privacy, and security [14]. It is prudent of the research team to create an environment that is safe for everyone, and an environment that honors the rights and values of all team members [15]. For instance, allow additional time for refugees to decide; such as committing to the collaboration or giving consent for participation. Obtain the proper permission from community members to provide the refugees with the reassurance that can reduce fears of being in trouble for participating in the research. It is imperative to listen and value the input and insights from the refugee partner [15]. Incorporate only team members who show the refugees respect, acceptance and empathy [16]. Researchers can benefit from having someone on the team that the refugees feel comfortable advocating for their concerns given that they are learning to trust the team. It is important to create and maintain a safe environment for the refugees when they are involved in any stage of the research process [14].

When communicating with the refugees, or the refugee community about research it is essential to avoid jargon and acronyms [16]. Using jargon and acronyms can make those who do not know them feel left out and can lead to confusion. Keep the information short, and to the point to avoid stress from information overload and confusion. Have regular and open communication with the refugee and refugee community members on the team to ensure everyone is on the same page and address concerns immediately.

During participant recruitment, word of mouth recruiting works best with most refugee communities [17]. A researcher should allow additional time for word-of-mouth recruitment [14]. It is advantageous to find key members of the community to connect the team to obtain the right data. Acknowledge and show respect for the refugees' efforts and time with honorariums, assisting with child care, and reimbursing travel when appropriate [10]. Critically reflect on the project regularly, to assist the team and allow the project to grow from the relationship and effort.

Conclusion

Our reflection reveals unique challenges that researchers may want to anticipate and outline a plan to effectively address when partnering with refugees. Sensitivities, ideas, emotions and life experiences

of the refugee community intersect with patient-oriented research. Refugees are an integral part of Canada's composition, and are essential for fostering validity and applicability of health research. Researchers must be mindful and show respect, empathy, and acceptance to create a culturally appropriate and safe environment in research.

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