

Tool for the Meaningful Consideration of Language Barriers in Qualitative Health Research

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Abstract

Individuals who experience language barriers are largely excluded as participants from health research, resulting in gaps in knowledge that have implications for the development of equitable policies, tools, and strategies. Drawing on the existing literature and on their collective experience conducting occupational health research in contexts of language barriers, the authors propose a tool to assist qualitative researchers and representatives from funding agencies and ethics review boards with the meaningful consideration of language barriers in research. There remain gaps and debates with respect to the relevant ethical and methodological guidance set forth by funding agencies and institutions and proposed in the scientific literature. This article adds to knowledge in this area by contributing our experiences, observations, and recommendations, including around the issue of conducting research in contexts of more or less linguistic diversity.

Keywords

language barriers; non-English speakers; exclusion from research; research tool; research methods; qualitative research; qualitative; Canada

Introduction

Canada is a linguistically diverse country, with 20% of the population reporting a nonofficial language¹ as mother tongue (Statistics Canada, 2015a), most commonly Mandarin, Cantonese, and Punjabi (“2016 Census,” 2017). In Toronto, Canada’s largest city, that proportion is 43% (Statistics Canada, 2015a). Evidence shows that among this population, those who experience language barriers also experience poor social, economic, and health outcomes and difficulties accessing care and other services (Asanin & Wilson, 2008; King, Lindsay, Klassen, Esses, & Mesterman, 2011); yet they are largely excluded as participants in health research (Brodeur, Herrick, Guardioloa, & Richman, 2017; Egleston et al., 2015; Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996; Murray & Buller, 2007). Common reasons include a lack of consideration by researchers, perhaps due to their own positionality as predominantly nonracialized (Henry, Dua, Kobayashi, James, Li, Ramos, & Smith, 2017; Peshkin, 2001); the cost, time, and complexity involved; and the specialized knowledge and experience required (Frayne et al., 1996). Adding to these challenges, governmental and institutional ethical and methodological guidance is lacking (Glickman et al., 2011; Jones & Resnik, 2006), while there remain gaps and debates with

respect to the guidance provided in the scientific literature (Croot, Lees, & Grant, 2011; Squires, 2009; Temple & Young, 2004). This article builds on the existing literature and on our collective field experience in occupational health to propose a tool to assist qualitative researchers, as well as funding agencies and ethics boards, with the meaningful consideration of language barriers throughout the research process. Here we define language barriers not as a trait of individuals but as a characteristic of the context.

Language Barriers and Occupational Health

The important role of language in shaping occupational health has been documented by researchers and recognized

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by policy makers. Language barriers contribute to employment in low-prestige,² manual jobs (Premji, Duguay, Messing, & Lippel, 2010; Smith, Chen, & Mustard, 2009) and to increased exposure to harmful conditions within jobs (Premji, Messing, & Lippel, 2008). Byon, Zhu, Unick, Storr, and Lipscomb (2017), for instance, found that language barriers were associated with patient violence among home care providers. As a result of these disproportionate exposures, rates of occupational injuries, illnesses, and deaths are elevated among workers who experience language barriers compared with their more fluent counterparts (Premji & Krause, 2010). Moreover, language barriers contribute to difficulties for workers to report injuries and illnesses (Menzel & Gutierrez, 2010; Scherzer & Wolfe, 2008) and to access and navigate workers' compensation systems (Gadoury & Lafrance, 2016; Gravel et al., 2010; Kosny et al., 2012; Premji, 2015). Barriers related to immigrant and racialized status combine with language barriers to increase workers' occupational exposures and associated health burdens, and they complicate care and compensation (McLaughlin & Hennebry, 2013). Unsurprisingly, regulatory bodies such as the Ontario Ministry of Labor have identified individuals who experience language barriers, and groups with a high representation of such individuals (e.g., recent immigrants), as "vulnerable workers"³ (T. Dean, 2010).

Despite this, occupational health research frequently excludes the voices of those who experience language barriers, even when the research is conducted on sectors or occupations where they are overrepresented. For example, as part of a qualitative study of workers' safety in the temporary agency sector in Ontario (MacEachen et al., 2012), a sector that draws many non-English speakers (Ng et al., 2016), researchers conducted interviews in English only (A. Kosny, personal communication, September 12, 2018). Echoing common practices (Murray & Buller, 2007), the researchers did not provide information on the language of participants in their reporting nor justification for the exclusion of non-English speakers. Moreover, information on participants' language is sometimes lacking even when interviews are conducted in other languages. In their study on recent immigrants to the Mississauga, Ontario area, J. A. Dean and Wilson (2009) explored the link between employment and health through interviews conducted in English and in other languages with the assistance of interpreters (J. Dean, personal communication, September 29, 2018). However, the languages spoken by the participants and the involvement of interpreters are not mentioned in their publication.

The exclusion of individuals who experience language barriers from occupational health research contributes to a superficial understanding of how language shapes experiences in different contexts. This is illustrated by the fact

that language and cultural barriers are frequently used interchangeably in occupational health research (Côté, 2013). In this way, language barriers are decontextualized and framed as a deficit among individuals, which can deflect attention from systemic factors and inadvertently result in victim blaming. Exclusion based on language may also result in the de facto underrepresentation of immigrant or racialized groups, and their experiences, issues, and concerns, from research (Hussain-Gambles, Atkin, & Leese, 2004). Given that a greater proportion of immigrant women than men lack official language proficiency upon arrival to Canada—48% versus 34%—and over time (Statistics Canada, 2015b), immigrant women, in particular, may be underrepresented in research. These knowledge gaps have important implications for the development of sound policy, practices, and tools in areas such as social and economic integration, employment, health and safety, health care, and workers' compensation, and more generally for the advancement of social justice. Importantly, these gaps are reflective of larger trends in health and qualitative research (Egleston et al., 2015; Murray & Buller, 2007).

Ethical and Methodological Guidelines

In Canada, the Tri-Council Policy Statement or TCPS 2 (2014) on ethical conduct for research involving humans notes that

researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion. (article 4.1)

The TCPS 2, which is a joint policy of the three federal research agencies—the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC)—do not, however, provide guidance on valid reasons for exclusion, nor do they address important ethical and methodological questions, such as how to obtain informed consent in a context of language barriers.⁴ Research ethics boards at some Canadian institutions such as the University of British Columbia provide limited relevant guidance on issues of equity and consent based on the TCPS 2, while others, including major research institutions such as McMaster University, lack any guidance on the topic. In the United States, reviews of federal and Institutional Review Board policies, guidelines, and regulations for research with participants who experience English-language barriers similarly found

wide variations between institutions in whether and what guidance is provided (Frayne et al., 1996; Glickman et al., 2011; Jones & Resnik, 2006).

The scientific literature, on the other hand, outlines best practices for the inclusion of participants who experience language barriers in qualitative research, with a particular focus on recruitment (Alvarez, Vasquez, Mayorga, Feaster, & Mitrani, 2006; Rugkåsa & Canvin, 2011), interpretation and translation (Chiumento, Rahman, Machin, & Frith, 2017; Esposito, 2001; Squires, 2009; Temple & Young, 2004), reporting (Oliver, Serovich, & Mason, 2005; Temple & Young, 2004), and working with communities (Berman & Tyyskä, 2011; Casado, Junko Negi, & Hong, 2012; Chidarikire, Cross, Skinner, & Cleary, 2018). Other aspects of the research process such as how to define and assess language barriers, or how to communicate with participants prior to the interview or focus group discussion, have received less attention in the scientific literature. In addition, the implications of working in contexts of more or less linguistic diversity have rarely been considered. There are also debates with respect to existing guidance, for instance, as relates to the role of interpreters as neutral transmitters of information or co-constructors of the data, reflecting the diverse epistemological positions of qualitative researchers (Squires, 2009; Temple & Young, 2004). Given the multiplicity of worldviews, Croot and colleagues (2011) have argued that guidelines may only be useful as a “sensitizing guide” to help evaluate fitness of methods and promote process transparency. We approach the tool proposed in this article from this perspective.

Tool Development and Parameters

The authors, who come from the fields of labor studies, public health, and occupational health and include mid- and early-career researchers, drew on their experience conducting qualitative research in the Canadian provinces of Ontario and Quebec over the last 15 years. Specifically, they drew on six studies that had varying aims with regard to the theme of occupational health and were conducted among different populations; however, all studies included participants who experienced language barriers, and they examined the role of language barriers either as the primary research objective or as a subquestion. The studies reported were approved by relevant ethics committees (Table 1). The authors discussed their experiences, observations, and recommendations with respect to conducting research in a context of language barriers, critically reflecting on each stage of the research process and drawing from the studies as appropriate. The authors developed their reflections in meetings and through the collaborative and iterative drafting of this article and consulted field notes and transcripts as

needed. They also drew on previous work that has addressed the unique methodological issues involved in conducting research in contexts of language barriers (Casado et al., 2012; Chiumento et al., 2017; Esposito, 2001). From this reflection, they inductively developed a tool composed of a set of questions pertaining to different stages of the research process, from conceptualization to dissemination, to be considered by qualitative researchers in the research planning stages or to be used as criteria by ethical review boards and funders to assess the consideration of language barriers in research proposals (Table 2).

Tool for the Meaningful Consideration of Language Barriers in Qualitative Research

Conceptualizing the Research

Few researchers include participants who experience language barriers in their research and even fewer consider doing so during the study design stage (Frayne et al., 1996). Researchers should consider whether and how to include individuals who experience language barriers early in the research process to ensure that inclusion is meaningful and that budgetary and logistical implications are considered. The focus of the research may, in some cases, justify exclusion. For instance, a hypothetical study of the mental health of 911 operators in Toronto would by default exclude non-English speakers because all operators are required to speak English as part of their job. There may also be valid methodological or conceptual justifications for exclusion, though the TCPS 2 does not provide such guidance, while some research ethics boards offer it in a limited way.⁵ Questions also remain about whether and in which scenarios research ethics boards should regard the lack of resources as a valid reason for exclusion.

In most studies, however, there is an opportunity to generate an understanding of the experiences, issues, and concerns of diverse communities by ensuring that individuals who experience language barriers can participate. Researchers may also work with community members or organizations as investigators and/or partners; however, we note the importance of challenging assumptions about representativeness and linguistic or cultural familiarity (Casado et al., 2012) and of taking into account issues of power and authority in the research process, in line with best practices for community-based research (Berman & Tyyskä, 2011; Shklarov, 2007). The benefits of working with communities was made evident in Study A, which explored the employment integration of immigrants and refugees, and in the context of which we worked with peer researchers who were fluent in Arabic and English and had community connections, but lacked research

Table 1. Characteristics of Selected Studies Conducted by the Authors.

	Title, Location (Year)	Research Aim	Representative Reference	Participants/Language of Interviews	Method
A	Safe Employment Integration of Recent Immigrants and Refugees, Ontario (2016–2017)	Examine the work integration process for recent immigrants and refugees and determine training and resource needs and opportunities	Kosny et al. (2018)	110 recent immigrants and refugees/English and Arabic	Focus group discussions/peer researchers, Arabic-speaking team member
B	Access to Workers' Compensation for Injured Workers who Experience Language Barriers (2016–2018)	Compare workers' compensation policies and practices in Ontario and Quebec as they impact access for workers who experience language barriers	Premji et al. (2019)	27 injured workers experiencing language barriers/English, French, Mandarin, Arabic, Patois, Korean, Portuguese, Spanish, Turkish, Russian, Cambodian, Persian	Interviews/professional interpreters
C	Health and Safety of Immigrant Workers in a Garment Factory, Montreal (2004–2006)	Describe the mechanisms by which language proficiency influences occupational health	Premji, Messing, and Lippel (2008)	25 immigrants/English, French, Chinese, Turkish, Tamil	Interviews/volunteer interpreters
D	Precarious Employment and Difficult Daily Commutes, Toronto (2014–2015)	Investigate the relationship between precarious employment and daily commutes at the intersection of gender, class, and migration	Premji (2017)	27 immigrants recruited principally from Bengali-, Spanish-, and Somali-speaking communities/English, Spanish	Interviews/professional interpreter
E	Precarious Work Experiences of Racialized Immigrant Women, Toronto (2011–2014)	Examine the precarious work experiences of racialized immigrant women	Premji et al. (2014)	30 racialized immigrant women/English, Arabic, Dari, Nepali, Sgaw Karen, Somali	Interviews/peer researchers
F	Delicate Dances: Immigrant Workers' Experiences of Injury Reporting and Claim Filing, Toronto (2010–2011)	Examine new immigrants' experiences after a work-related injury	Kosny et al. (2012)	28 injured immigrant workers/English, Cantonese, Mandarin, Spanish, Tamil, Arabic, Gujarati, Bengali, Polish, Ukrainian, Punjabi	Interviews/professional interpreters

experience and training. Peer researchers contributed to all aspects of the project, and the benefits of their participation far outweighed the additional time and costs involved with their recruitment, training, and mentoring. As in other studies (Berman & Tyyskä, 2011; Chidarikire et al., 2018), they helped shape the research questions to address issues that were important for their communities, offered nuance and rich insights throughout, and promoted the participation of traditionally excluded populations, in part, by allowing them to express themselves in their own language. The approach also enhanced the skills of the peer researchers and promoted long-term collaborations with community members and agencies.

Defining Language Barriers

Language barriers are defined variably in different geographical and social settings, and researchers should consider the type and degree of language skills or barriers

that are relevant to their particular context. In Study B, which examined workers' compensation access in two provinces, researchers defined language barriers as difficulties communicating in English in Ontario and French in Quebec, and determined that the entire continuum of language barriers, including having an accent, needed to be considered. They further determined that dimensions of spoken proficiency in the majority language and written proficiency in any language were relevant to workers' compensation access. Untangling the context-specific nuances of how language barriers are experienced can help ensure that individuals who experience barriers in a less noticeable way are also included in research.

When language barriers are a selection criterion, as in Study B, researchers should determine the manner in which language barriers will be assessed. We have always relied on participants' self-assessment of their language skills through screening questions such as "Do you have difficulties communicating in English, verbally or in

Table 2. Tool for Researchers, Funding Agencies, and Ethics Boards for the Meaningful Consideration of Language Barriers in Qualitative Research.

Research stage	Questions
Conceptualizing the research	<ul style="list-style-type: none"> • Is there a valid methodological or conceptual reason to exclude participants who experience language barriers from the research? • How can individuals who experience language barriers be included as participants, investigators, and/or partners? How will their participation be operationalized? For example, if including peer researchers, who will train them, and in what? Have issues of representativeness and power been considered? • How can the research help address issues of concern to communities who experience language barriers?
Defining language barriers	<ul style="list-style-type: none"> • What types and degree of language skills or barriers are relevant to the study context? • If language barriers are a selection criterion, how will they be assessed? • What descriptor will be used to refer to individuals who experience language barriers? Is the descriptor accurate and considerate of the communities concerned?
Delimiting the sample	<ul style="list-style-type: none"> • From which language groups will researchers sample? How will the languages be chosen? • What are the benefits and limitations of this sampling strategy? Does it lead to equity concerns?
Recruiting participants	<ul style="list-style-type: none"> • Who will recruitment efforts target and why (if different from the sampling population)? • What strategies will be used to recruit individuals who experience language barriers? Do recruitment strategies give rise to ethical concerns or biases and limitations? • What recruitment materials will researchers translate and into what languages? • Is the language or translation(s) of the recruitment materials appropriate (e.g., dialect, wording)? • Have socioeconomic barriers to recruitment been considered (e.g., child care, transportation)?
Communicating prior to data collection and ensuring informed consent	<ul style="list-style-type: none"> • How will researchers communicate with potential participants who experience language barriers prior to data collection? Does this method promote informed consent? • Will consent forms be translated? If not, what method will be used to ensure informed consent is acquired and documented? • Have researchers made assumptions about participants' ability to read and understand the consent form?
Collecting data	<ul style="list-style-type: none"> • Will the interview or focus group discussion be conducted in society's majority language, in the participant's language, or with the help of an interpreter? What are the benefits and limitations of the chosen strategy? • If working with an interpreter or peer researcher, have their credentials and roles been considered? • What training will interpreters or peer researchers receive, and who will provide it? Will the participant be briefed on the role of the interpreter? • Have issues of positionality been considered? • How will interpretation be evaluated on an ongoing basis and checked for quality?
Managing data	<ul style="list-style-type: none"> • If data are collected in the participants' languages(s), by whom and when will it be translated? • Have potential political and methodological issues with translation been considered? • Will researchers develop a translation and transcription protocol and will they keep a log of decisions? • How will the translation and transcription be checked for quality? • Will interpreters, translators, and transcribers sign confidentiality forms?
Reporting results	<ul style="list-style-type: none"> • Will the reporting include quotations from individuals who experience language barriers? • Has the potential for voice appropriation been considered and minimized? • Will researchers make the interpretation and translation visible in their reporting? Will they report on the language composition of participants, and language-related research procedures and eligibility criteria?
Disseminating results	<ul style="list-style-type: none"> • Have issues of language and communication been considered for the dissemination of results? • How will researchers ensure that the communities of interest benefit from the research results? • Will tools, knowledge, and strategies reflect the needs of and be accessible to individuals who experience language barriers?

writing?" Interestingly, participants' self-assessment of their language skills sometimes clashed with our informal assessment, as we received telephone and email inquiries from individuals who did not immediately appear to

experience language barriers. With few exceptions, interviews revealed that language barriers did in fact exist for these participants. Namely, they could speak English but experienced difficulties writing it, or vice versa, or their

English was sufficient to read and respond to the advertisement and negotiate an interview with researchers but insufficient to navigate the workers' compensation system.

In addition, researchers should carefully consider the terms used to describe individuals who experience language barriers to ensure that they are both accurate and considerate of the perspectives of the communities involved. In Study A, Amharic and Persian translators suggested that the term "linguistic minority" be avoided as they felt it denoted an inferior status and could be considered offensive. The minority label is also contextually specific as one can simultaneously be a minority in one context and a majority in another. When researching hotel room cleaners in Las Vegas, Premji and Krause (2010) observed that those with English as a second language, who were the majority among hotel room cleaners, had established networks for information and support that might explain their higher rates of claim filing compared to other injured workers. However, as a minority in relation to the workers' compensation system, they struggled to get their work injuries recognized and compensated. In this article, we refer to individuals "who experience language barriers" to support the perspective of barriers as external rather than intrinsic to individuals. Naming the experience of language barriers also avoids the use of language-specific descriptors, such as "low English proficiency," as we at times refer to contexts where English is not the majority language.

Delimiting the Sample

In some cases, individuals who experience language barriers may be members of one or a limited number of language groups. For example, researchers studying health and safety among day laborers in California and interested in including the voices of those who experience language barriers may only need to sample from Spanish speakers. In other cases, where the population is linguistically diverse, researchers may sample from a few or all language groups. To sample from a few groups, they may select languages with community partners, choose languages that are spoken by researchers, and/or choose the most common languages for their study context. The strategy of limiting sampling to a few groups has a number of practical advantages, such as minimizing costs associated with the translation of recruitment materials and consent forms, targeting recruitment efforts at particular communities, and improving interview quality by working with the same interpreters or with peer researchers (Kosny, MacEachen, Lifshen, & Smith, 2014). However, in the context of Study B, this strategy, used initially, hindered recruitment by further restricting the study population, which was already narrowly defined by

the research question. In addition, this approach can lack a strong theoretical basis and may lead to equity concerns. For example, researchers involved in Study A found that the initial emphasis on Syrian refugees was problematic, with one participant noting that "all the attention are given to the Syrian refugees but all other refugees are going through the same challenges." As a result, researchers included other Arabic-speaking refugees in the focus group discussions. Focusing on groups that receive more attention or that are larger in size can obscure the experiences of less visible or smaller communities. On the contrary, recruiting from all language groups, as we eventually did in Study B, poses a number of practical challenges for recruitment, consent, data collection, and dissemination, as we discuss below.

Recruiting Participants

Participants who experience language barriers may be difficult to recruit because they may not respond to traditional recruitment methods such as advertisements (McLean & Campbell, 2003; Thomson & Hoffman-Goetz, 2011) or they may mistrust researchers, particularly when they come from communities that have traditionally been excluded from or exploited in research (Barata, Gucciardi, Ahmad, & Stewart, 2006; Pacheco et al., 2013). They may also experience other barriers to participation, such as precarious social and economic conditions. In our projects we have had limited success recruiting participants "passively" through ads placed in community locations (e.g., grocery stores), in newspapers, on social media, and on popular online advertisement platforms. As others have noted (Alvarez et al., 2006; Casado et al., 2012; Rugkåsa & Canvin, 2011), and as we have found, working with members of the community is much more effective for recruiting participants who experience language barriers, though it is generally not recommended to work with communities solely for the purpose of recruitment as the strategy can be exploitative. Also, while this recruitment strategy can be effective, researchers should be aware of the potential for coercion (Rugkåsa & Canvin, 2011) and for miscommunication of selection criteria by intermediaries, which may be amplified in a context of language barriers. This strategy may also impact the generalizability of results. In Study A, researchers worked closely with settlement agencies to recruit participants, but since participants were receiving language and employment assistance, the knowledge researchers gained on employment experiences and health and safety knowledge could not be generalized to the majority of individuals who do not have contact with such agencies.

To assist with recruitment, researchers should translate promotional materials, which is costlier when recruiting

from multiple language groups and when the research team lacks the necessary language skills. In this scenario, any post-translation changes to the recruitment material, even minor, can add up to significant costs. Researchers interested in recruiting from all language groups may therefore still need to target recruitment to particular communities to minimize costs. In Study B, researchers decided to open recruitment to members of any language group but, as they could not translate materials in upward of 200 languages, they continued to advertise the study in a few languages chosen with community partners or because they were the languages spoken by volunteer translators recruited from within the researchers' networks. Participants from other language groups were informed about the study through the English or French recruitment materials and, like other participants, they were offered the assistance of an interpreter for the interview. In considering recruitment materials, researchers should also evaluate the appropriateness of the language and wording and their translation. In Study A, potential participants contacted researchers to ask if they could help them find work after seeing the advertisement for the research on Facebook, which described the study as a group conversation about experiences with finding employment. The advertisement, in Arabic, also mentioned a "\$20 honorarium," which was a gift card but was interpreted by some as cash. To avoid participants feeling deceived, researchers changed the wording to a "\$20 gift card." Finally, in devising their recruitment strategy, researchers should consider offering meaningful compensation as well as reimbursing transportation and child care expenses to ensure that socioeconomic barriers to recruitment are minimized.

Communicating Prior to Data Collection and Ensuring Informed Consent

Researchers need to establish how they will communicate with potential participants prior to data collection, to determine eligibility, set up the interview time and location, provide information about the study, and otherwise ensure informed consent. This communication can be challenging when the research team lacks the necessary language skills. Some institutional guidelines, such as those of the University of British Columbia, recommend the assistance of an interpreter during the informed consent process and ongoing interactions with participants who experience language barriers. The risk of not working with an interpreter was made evident in Study C (a doctoral thesis) when a researcher interviewed a participant who appeared to believe that his work was being evaluated on behalf of his employer. The researcher's language was French, which the participant spoke with a heavy accent, and

neither the participant nor the researcher felt it necessary to have an interpreter present when communicating prior to and during the interview. The participant may however have lacked sufficient French language skills to fully understand the purpose of the research and the role of the researcher. It is therefore prudent, prior to data collection and even when language barriers do not significantly preclude communication, to communicate with participants in the language in which they are most comfortable or at least have an interpreter present to assist if needed. In our experience, participants sometimes decline the offer of an interpreter, and researchers should explain his or her importance and role to participants. Researchers may work with professional interpreters, volunteer interpreters, or research team members with the required language skills to communicate with potential participants. Working with professional and volunteer interpreters in this context can be expensive and difficult if an interpreter needs to be requested ahead of time, particularly when potential participants reschedule interviews or fail to answer the phone. The growing popularity of instant professional interpretation services billed by the minute and without minimum fees presents a cost-effective option to promote effective communication between researchers and potential participants at this stage of the research.

To ensure informed consent in contexts of language barriers, available institutional guidelines also typically advocate for the use of translated consent forms, despite concerns about readability even for participants who do not experience language barriers (Jefford & Moore, 2008; Paasche-Orlow, Taylor, & Brancati, 2003). In the United States, the federal government similarly requires for its funded research that the informed consent document be available in a language understandable to the participant, noting that routine ad hoc interpretation of the consent form should not be substituted for written translation unless a non-English-speaking participant is unexpectedly encountered, in which case a short-form written consent document in the participant's language should be used (U.S. Food and Drug Administration, 2018). In California this document is called the "Research Participant Bill of Rights" and is available online in multiple languages (Office of the Human Research Protection Program, 2012). The University of British Columbia, on the contrary, discourages the use of short-form consent documents because it prefers for full consent to be obtained through the translation of the consent form or by working with an interpreter (J. Ruiz, personal communication, October 2, 2018). Warning against oral consent, the U.S. federal guidance states that "Investigators should carefully consider the ethical/legal ramifications of enrolling subjects when a language barrier exists. If the subject does not clearly understand the information presented, the

subject's consent will not truly be informed and may not be legally effective." However, it remarks that participants who speak and understand English but do not read or write it may be enrolled in a study by "making their mark" on the consent document, which should outline the method of communication with the participant and the means by which he or she communicated consent (U.S. Food and Drug Administration, 2018).

When the languages spoken by potential participants are numerous or cannot be anticipated, translating consent forms can be costly and impractical. In one of our ongoing studies, we estimated that translating consent forms for 30 participants who might potentially speak different languages could amount to Can\$9,000, as professional translation costs can be upward of Can\$300 per consent form. As a result, with assistance from the research ethics board at McMaster University, we developed an informed consent script for interpreters in lieu of a translated consent form. The script provides instructions for the interpreter (e.g., to interpret as closely as possible rather than to summarize), as well as questions to be asked by the interpreter to check the participant's understanding after each short section (e.g., "Do you understand what the study is trying to do?" "Do you understand how to drop out of the study if you decide to do that?"). The process can be lengthy, however, as it emphasizes making sure that the participant has a full understanding of the purpose of the study, their participation, the possible risks, and the ways in which the researchers will handle the data. Consent is recorded through an oral consent log, and participants are provided with an English consent form with the researchers' contact information for reference. We have found this alternative useful when conducting research in contexts where we might encounter participants from many language groups. This approach may also be useful in cases of potential illiteracy, noting that researchers should avoid making assumptions about participants' ability to read and understand the consent document. One participant in Study A, for example, had sufficient English language skills to participate in the English focus group discussion but had difficulties understanding the English consent form (researchers in this case provided her with an Arabic consent form). When possible, researchers should provide the consent form, whether or not translated, to participants ahead of the interview or discussion and verbally review it prior to data collection. Doing so aligns with best practices that advocate for a process of giving information and seeking consent throughout the research (Berg, Lune, & Lune, 2004).

Collecting Data

Interviews and focus group discussions may be conducted in society's majority language, in the participant's

language by a researcher who speaks that language, or with the help of an interpreter. This decision is made based on the availability of resources and the research approach and has the potential to shape the interpretive theories arising from the work (Tarozzi, 2013). Conducting interviews and focus group discussions in society's majority language has benefits. Kosny, MacEachen, et al. (2014) described how interviews without interpreters were easier to manage, more relaxed, and revealed richer and more nuanced information. However, in other studies we observed that English-language interviews with participants who experience language barriers may lead to misunderstandings of questions or concepts and reveal limited information. In Study A, participants in the English discussions generally misunderstood the concept of occupational health and safety as relating to the health and safety of clients, customers, and patients rather than that of workers. We also observed that participants in the English focus group discussions were less likely to be open and expressive when other participants had a stronger command of the language. For interviews and discussions conducted in society's majority language, it may still be helpful to have someone present to interpret if need be. In Study A, the moderator, who spoke Arabic, was able to occasionally translate words that participants had difficulty understanding in the English discussions.

Conducting interviews and focus group discussions in the participant's language represents another strategy. This can be achieved by research team members who speak the language, such as peer researchers, or by working with interpreters. The epistemological position of the research has implications for that individual's role either as cultural broker, where he or she conducts the research as a key informant, or as a neutral transmitter of information hired only for the purpose of interpretation (Temple & Young, 2004). Data collection in the participant's language by researchers who speak the language has many advantages. In Study A, we found that the Arabic group dynamics were less formal and seemingly more enjoyable for participants compared with the English-speaking groups, which could be due to participants feeling more comfortable to verbalize their thoughts, and to their shared linguistic and cultural background with other participants and the interviewer. Researchers who speak the participants' language can help navigate cultural differences (Temple & Young, 2004). In Study D, for instance, a female Muslim peer researcher interviewing a male Muslim participant avoided questions about the impact of precarious employment on family dynamics, deeming them inappropriate in that context. However, others have pointed out that while researchers and participants may share a language, socioeconomic differences may impede effective communication (Lee, Sulaiman-Hill, & Thompson,

2014). There are also concerns about confidentiality when the researcher and participants are from the same community. In Study E, where we worked with peer researchers, we addressed this concern by using a rigorous informed consent process, having the peer researchers sign confidentiality agreements and undertake confidentiality training, and having a team member unknown to the participant conduct the interview when possible (the latter has also been proposed by Jentsch, 1998).

Interpreters, on the contrary, may be professional or lay (typically volunteers). Chiumento and colleagues (2017) have suggested that professional interpreters are more likely to use language unfamiliar to participants than lay interpreters, while Jentsch (1998) found that lay interpreters sometimes answered questions for participants, an issue we also experienced in Study C (a doctoral thesis) where, to minimize costs, we worked with volunteer interpreters who were colleagues or friends of the participants. Relying on participants' friends and family for interpretation may also jeopardize confidentiality and limit the information shared with researchers. Whether professional or volunteer, there is a debate around the role of interpreters as conduits, advisers, or advocates (Temple & Young, 2004), though in reality they often play many roles (Hsieh, 2008). In contrast to positivist frameworks that view the interpreter as a research instrument (Esposito, 2001), constructionist researchers have argued that interpreters are involved in a three-way co-construction of data (Björk Brämberg & Dahlberg, 2013), and that they are "active producers in research rather than neutral conveyors" (Temple, 2002, p. 846). From this perspective, priority is given to meaning over word-for-word translation.

We have found that interviews conducted with interpreters typically take longer, impacting the costs associated with interviewing, interpretation, and transcription. Working with interpreters may also impact researchers' ability to complete the interview in the usual time frame. In Study B, injured workers' trajectories often had gaps that could have been filled by conducting a second interview. In a previous publication (Kosny, MacEachen, et al., 2014), and based on Study F, the authors discussed some of the additional practical challenges involved in working with interpreters, such as variation in interpreter skills, methods, English proficiency, and adherence to interview conventions. Researchers have proposed guidance for working with interpreters with regard to training and supervision on aspects such as the research topic and interview questions, interpreter role and interpreting guidelines (e.g., focus on words or meaning), research ethics, and professional conduct (Björk Brämberg & Dahlberg, 2013; Chiumento et al., 2017; Jentsch, 1998). Due to the time and effort involved in training, it is

generally preferable to work with the same interpreters repeatedly (Squires, 2009; Wallin & Ahlström, 2006), although this may not be possible when working with many language groups. Researchers should also pay attention to how issues of positionality may impact narratives and the validity and reliability of the data obtained (Jentsch, 1998). According to the TCPS 2, "The researcher should select an intermediary with the necessary language skills to ensure effective communication" (article 4.1); however, factors such as origin, religion, dialect, gender, and political views should also be considered (Chiumento et al., 2017; Hadziabdic & Hjelm, 2014), while recognizing that social matching of interpreters and participants can both stimulate and hinder communication (Temple & Young, 2004). Finally, interpretation may not reflect participants' detailed meaning, and words and concepts may not translate well culturally or linguistically (Birbili, 2000; Hunt & Bhopal, 2003; Van Nes, Abma, Jonsson, & Deeg, 2010).

All of these issues pose validity threats at various points of the interview because the interviewer, for example, may not know whether the participant's responses have been summarized or modified (Kapborg & Berterö, 2002). It is therefore recommended that researchers have ongoing discussions and debates with interpreters about issues of both practical and conceptual significance (Temple, 1997), discuss interpretation issues during research meetings, and conduct quality checks for interpretation or translation (Björk Brämberg & Dahlberg, 2013; Chiumento et al., 2017; Lincoln & Guba, 1985). For instance, Inhetveen (2012) compared oral interpretation during interviews and written translation from audio files after interviews by the same person, and found that the two approaches produced different sets of data.

Managing Data

If an interview or focus group discussion is conducted in another language, the audio files or transcripts will usually need to be translated (Esposito, 2001). In Study A, peer researchers translated and transcribed in one step. However, despite training for all peer researchers on translation and transcription, two produced incomplete transcripts and only included information they thought relevant. As a result, the in-between conversations that often arise in focus group discussions, which may not directly answer the research questions but may offer valuable insights, were discounted. The two peer researchers were certified interpreters who provided services to immigrants and refugees (for instance, for doctor visits), so it is possible that they were accustomed to summarizing information rather than verbatim interpretation and translation. This issue was discovered by a bilingual researcher who spoke the participants' language and

reviewed the transcripts with the audio file. Others have similarly suggested that someone not involved in the data collection or initial translation validate the translation (Clark, Birkhead, Fernandez, & Egger, 2017; Squires, 2009). Validation may also be done through a process of back translation, or translating text back into its original language (Chen & Boore, 2010), while Casado et al. (2012) have argued that it may be more effective to first produce a verbatim transcription in the participant's language, translate the transcript, and have multiple translators review both. We have not used the approach of back translation nor of translating and transcribing in two steps as we have found it prohibitively costly for transcripts. However, rather than treating validation as a "step," it has been argued that researchers should consult with bilingual individuals around the use and meaning of words in a process of reciprocity throughout the research, including in the development of instruments, to improve conceptual equivalence and minimize the issues of validity with forward and back translation (Birbili, 2000; Larkin, Dierckx de Casterlé, & Schotsmans, 2007).

Some have argued that translation should be done in the early phases of a study because it allows more interaction around data analysis among researchers and translators as well as access to the entire dataset for researchers who do not speak the participants' language(s) (Santos, Black, & Sandelowski, 2015). An alternative is to conduct the analysis in the participants' language(s) and only translate emerging concepts and categories (Chen & Boore, 2010) or sections that are to be published (Chiumento et al., 2017). This approach may help retain the full nuance of meaning in the original language that may be lost when translation precedes analysis. Even when translating at the stage of publication, researchers should be aware of the potential semantic loss, the difficulties translating cultural meanings, and the potential political issues associated with rendering the source language invisible (Temple & Young, 2004). For example, for Study B, which compared compensation systems in Ontario and Quebec, we produced a report in English but left the French quotations. Some of the statements had been communicated by interpreters, which raised concerns about loss of meaning from multiple rounds of translation. In addition, we felt that leaving the French quotations made the report more accessible to our partners and colleagues in Quebec and avoided the dangers of presenting French speakers as English speakers in a province where assimilation concerns are paramount. Regardless of the approach, researchers should establish a translation protocol around issues of completeness, level of details, and content accuracy (Chiumento et al., 2017; Clark et al., 2017) and keep a log of their decisions (Santos et al., 2015). The protocol should also address transcription, as decisions will need to be made around

what is to be transcribed and whether and under what circumstance to edit for clarity (Oliver et al., 2005). As Tarozzi (2013) has argued, "Every transcription is also a translation" (p. 11). Importantly, researchers working with multiple transcribers and translators will need to consider how to properly handle data confidentiality.

Reporting Results

In reporting the results of the research, researchers should take care not to exclude the voices of participants who experience language barriers, particularly as they typically choose the most eloquent quotations to illustrate results. In Studies D and E, as researchers realized that almost all the quotations they presented originated from the few more eloquent participants, an effort was made to diversify the voices throughout the reporting. Researchers should also consider how editing for clarity at the transcription or reporting phases might inadvertently result in a form of linguistic whitewashing (Oliver et al., 2005). However, others have argued that presenting unedited quotations may be stigmatizing and lessen anonymity (Corden & Sainsbury, 2006). Researchers involved in Study D were confronted with this decision when asked by journal editors to edit the following quotation from a Jamaican Patois native speaker:

I would be concerned in winter because . . . you have to travel say an hour, hour and a half you have to leave home . . . it's dark. By the time you get home it's dark. So if you live in a dark street where it's isolated and some of the streets are residential streets. Many people don't walk, they have cars and if you have a low paying person that you don't have anybody to pick you up at the bus stop . . . then you have a concern because you have a lot of rapists that are walking on the street.

The editors asked researchers to change "if you have a low paying person" to "if you are a low paid person." However, the researchers felt that the wording did not detract from the meaning, while editing the quotation would take away from its authenticity (Premji, 2017). We therefore suggest that researchers edit quotations if unintelligible but still allow participants to speak in their own voices. In oral communications, researchers should also consider the potential dissonance when relating the stories of or reading quotations from participants who may be different from them in terms of status, appearance, or language. Across forms of reporting, there is an opportunity to minimize the potential for voice appropriation, whereby dominant voices tell the stories of or about subordinate groups, by working with members of those groups on an equal basis throughout the research process, including in presentations and publications (for an example, see Premji et al., 2014).

A related issue arises when the interpretation and translation are rendered invisible in the reporting. Typically, “Results are presented as if interviewees were fluent English speakers or as if the language they used is irrelevant” (Temple & Young, 2004, p. 163). This is due, in part, to peer-reviewed journal formats and requirements that preclude or fail to require descriptions of the complexity of the research process, and to disciplinary practices in fields that favor empiricism and objectivity (Malterud, 2001). Researchers should report on the role, credentials, and identity of the interpreter; the language of analysis and timing of the translation; and the ways in which interpretation or translation may have affected results (Squires, 2009). Similarly, Temple (2002) has argued that the “intellectual biographies” of interpreters who act as cultural brokers, including their relevant background, beliefs, views, and experiences, should be teased out. These recommendations echo constructivist arguments that support transparency about the researcher’s voice and the tribulations of the research process as means to assess the trustiness of the data (Carter & Little, 2007). Finally, researchers should report on the language composition of the participants, research procedures when the research includes participants who experience language barriers (e.g., how informed consent was obtained), as well as language-related eligibility or exclusion criteria and their justification and implications (Murray & Buller, 2007).

Disseminating Results

The TCPS 2 states that the benefits of the research should be distributed equitably and that results should be made available “in a culturally appropriate and meaningful format” (chapter 4). In line with ethical guidelines and best practices (Berg et al., 2004), research results should therefore be communicated while taking into account potential language barriers, for instance, by translating findings summaries. However, working with members of communities that have an interest in the research and its outcomes is most effective in terms reaching and benefiting those communities (Ferris & Sass-Kortsak, 2011). Researchers involved in Study C worked with union representatives and factory workers representing most of the languages spoken in the factory at various times over the course of the project. The workers were involved in shaping the research questions and the production of knowledge and recommendations, and they assisted with the dissemination of this information within members of their communities. In thinking about disseminating results, researchers should consider not only language but communication more generally. For example, researchers who developed a toolkit for settlement agencies to teach newcomers in Ontario about health and safety learned

from feedback from educators and new immigrants that the wording was too dense and that it was difficult for readers to identify the important sections. In response to the feedback, the research team included a glossary of key words and the modules were formatted to allow different delivery methods such as class discussion, exercises, and questions (Kosny, Lifshen, Smith, Saunders, & Rhooms, 2014). We therefore propose that researchers and policy makers look through the lens of language and intersecting factors that impact communication when developing knowledge, tools, and strategies to ensure that they reflect the needs of and are accessible to individuals who experience language barriers.

Conclusion

Researchers frequently fail to include participants who experience language barriers in their projects, in part, because they lack the knowledge and experience to do so. Given the increasing representation of individuals who experience language barriers in Canada and other immigration-receiving countries, their continued marginalization, and ethical standards related to equity and justice, researchers should consider the role of language barriers and actively seek to include individuals who experience them in their research. While our emphasis is on language, we recognize that other factors such as socioeconomic status, essential skills (e.g., reading, computer use) (Saunders, 2003), and culture (Côté, 2013; Premji, Lippel, & Messing, 2008) may also impact communication with research participants and should similarly be considered. However, like language, these factors should be framed as dynamic and systemic, for example, taking care to avoid framing culture as a fixed trait of homogeneous populations (Kleinman & Benson, 2006). This article builds on existing research and on our field experience to propose questions and recommendations for the meaningful consideration of language barriers in research. Ethical guidelines set by funding agencies and institutions provide limited ethical and methodological guidance, while there remain gaps and debates in the scientific literature. Our article addresses some of these gaps, including the implications of working in situations of extensive linguistic diversity such as in large urban centers where dozens of languages are represented.

While researchers need additional guidance on how to address some of the particular methodological challenges involved in conducting research in this context, they also need to comprehensively implement existing ethical and qualitative research guidelines. Funders, publishers, institutions, and researchers can all play a role in developing and implementing guidelines with the objective of promoting equity in health research. At the same time, funding agencies need to recognize the added costs of

inclusivity, such as costs related to translation of materials and interpretation of interviews or focus group discussions. As we have experienced and discussed, researchers must consider the cost implications of their decisions. They must weigh inclusivity (e.g., recruiting from all language groups) with its resource implications (e.g., cost of translating recruitment materials and consent forms). As budgets are cut, researchers may be forced to make choices that compromise inclusivity. The resulting knowledge gaps may lead to the invisibility of the experiences of immigrant or racialized groups, which may in turn contribute to a lack of attention by researchers on issues relevant to them, creating a vicious circle.

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Notes

1. Canada's official languages are English and French.
2. We use the expression "low-prestige" rather than "low-skilled" because tasks may require more skills than is obvious (Messing, 1998).
3. "Workers in situations of vulnerability" and related expressions are increasingly being used to refer to the source of vulnerability as external to the workers.
4. With regard to the inclusion of sex and gender, on the contrary, the CIHR has developed extensive interactive online competency modules for researchers and reviewers.
5. For example, the University of British Columbia Research Ethics Boards state that "Justification for excluding non English speaking participants may be appropriate in limited circumstances, such as when there are methodological limitations based on the lack of appropriate validated instruments, surveys or assessment. In some situations, use of another language may confound the research results or not permit appropriate analysis of the data especially when protocols are designed with a small sample size." UBC Research Ethics Board (2017).

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