Commentary: Developing Relationships through Trust in Indigenous Health Research

Commentaire : Développer des relations grâce à la confiance dans la recherche en santé autochtone

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Abstract

Developing strong relationships between researchers and Indigenous partners and communities is crucial for mutually beneficial and appropriate Indigenous health research. However, explanations on the need for strong relationships and how they may be achieved are not often found within the research literature. Given the history of mistrust, exploitation and even unethical research practices with Indigenous populations, collaborative research partnerships necessitate good relationships. For our long-standing community-based participatory research partnership, trust in our relationships has been foundational. Several key elements are central to developing this trust, including coming together in ceremony, practising humility and becoming personally and emotionally invested in each other's lives. We also prioritize time, effort and flexibility to actively work on our relationships. To make effective and beneficial change within Indigenous health research compels reframing western perspectives and overcoming long-standing institutional barriers, such that enduring and trusting relationships are the focus and not a means to an end.

Résumé

L'établissement de relations solides entre les chercheurs et les partenaires autochtones est essentiel pour une recherche en santé autochtone mutuellement bénéfique et appropriée. Cependant, les explications sur la nécessité d'établir de telles relations et sur la manière d'y

arriver ne sont pas souvent données dans la littérature scientifique. Compte tenu de l'historique de méfiance, d'exploitation et même de pratiques de recherche contraires à l'éthique avec les populations autochtones, les partenariats de recherche collaborative nécessitent de bonnes relations. Dans le cas de notre partenariat de recherche participative communautaire de longue date, la confiance dans nos relations a été fondamentale. Plusieurs éléments clés sont essentiels pour développer cette confiance, notamment se réunir lors de cérémonies, pratiquer l'humilité et s'investir personnellement et émotionnellement dans la vie de l'autre. Nous privilégions également le temps, les efforts et la flexibilité pour travailler activement sur ces relations. Pour apporter des changements efficaces et bénéfiques au sein de la recherche sur la santé autochtone, il faut recadrer les perspectives occidentales et surmonter les barrières institutionnelles de longue date, de sorte que des relations durables et de confiance soient au centre des préoccupations et non un moyen d'atteindre une fin.

We feel that it is important to begin with who we are and where we come from.

Richard Oster: My ceremonial name is Wâpastim (white horse). I come from mixed European descent, including Danish, Scottish, German, Austrian and Ukrainian ancestries. Since birth, I have called Treaty Six Territory and Métis Region Four in Alberta, home. My family has lived in this area for four generations, and I continue to live here with my fiancée (who is of Cantonese Han Chinese descent) to raise my two children.

Patrick Lightning: My name is Wapî-maskwa (white bear). I come from the Buffalo Child family (Albert Lightning) and the Bear Hills people of Maskwacîs, in Treaty Six Territory. My wife, Inez Lightning (yellow bird woman), is Anishinaabe. I have 10 children, 37 grandchildren and 10 great-grandchildren. I am Nêhiyaw (Cree) and live my life accordingly. I am a third-generation residential school survivor.

Introduction

Examples from two distinct Indigenous communities in the province of Alberta demonstrate that autonomy, self-determination and ownership in applying ways of knowing and expertise are key to strong community responses toward public health crises, such as the COVID-19 pandemic (Barnabe et al. 2022). This should not come as a surprise, as Indigenous peoples and communities are experts on the issues they face. The examples from Siksika Nation and the Métis Nation of Alberta are positive accounts of community-led efforts to support the well-being of community members during a global pandemic and the need to be heard. Strengths-based and community-driven stories that centre on Indigenous ways of knowing abound, yet the literature and media around Indigenous health remain overwhelmingly deficit focused, which can perpetuate inaccurate stereotypes and rhetoric (Bryant et al. 2021). Responsive, empowering, decolonizing and positive solutions to health issues are needed to move communities forward and ultimately reframe the issues so that they shame the underlying causes (such as the impacts of colonization and westernization, historical and intergenerational trauma and inequities in the social determinants of health), rather than shaming Indigenous peoples (Bryant et al. 2021; Snelgrove et al. 2014).

Barnabe et al. (2022) support upholding an approach of "self-determined service delivery and the incorporation of Indigenous culture" (p. 53) and indicate that it should be supported

by respectful relationships and collaboration. We agree, and the literature is clear on the need to develop collaborative relationships for Indigenous health research, healthcare innovation, policy advancement and societal reconciliation (Anderson 2019; Drawson et al. 2017). That said, in their article, Barnabe et al. (2022) provide little insight into *why* the development of strong relationships is needed or *how* this may be achieved. Herein, we seek to extend the discussion initiated in their paper, briefly discuss the necessity of relationship building in Indigenous health transformation and research and provide insights from our own relationship built through trust.

Relationships Are the Blueprint for Successful Research Partnerships

We will not discuss the health and social inequities faced by many Indigenous populations as this story is too often told in research literature (Bryant et al. 2021). Suffice it to say that there are marked disparities (King et al. 2009), such as life expectancy (Government of Alberta 2021), that are widening throughout Alberta. Transformational Indigenous health research is critical. However, the word "research" is often viewed negatively in many Indigenous communities as there has been a lengthy history of mistrust, exploitation and even unethical research practices (Hyett et al. 2018). Moreover, there are many examples of well-intentioned research studies with unintended consequences, such as "helicopter research," which has benefited the careers of researchers and western science as a whole but brought no tangible benefit to communities (Campbell 2014; Dudgeon et al. 2010). External observation of Indigenous subjects is another damaging pattern, which results in limited community input or control and top-down authoritarian prescriptions of what communities should be doing. Practices of this nature are not historical, but continue in the present day (Campbell 2014; Dudgeon et al. 2010; Hyett et al. 2018). These approaches are generally devoid of any vested, emotional concern for the Indigenous peoples and communities involved and are developed from a reality and perspective that is completely separate from and ignorant of those being researched.

Given the history of Indigenous health research – coupled with the ongoing impacts of colonization – new research practices founded on genuine relationships are needed. In Canada, most university ethics boards are now in line with the following: the chapter "Research Involving the First Nations, Inuit and Métis Peoples of Canada" of the *Tri-Council Policy Statement Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council 2018: 107–12); the principles of Ownership, Control, Access and Possession (The First Nations Information Governance Centre 2014); the Principles of Ethical Métis Research (NAHO n.d.); and the National Inuit Strategy on Research (Inuit Tapiriit Kanatami 2018). These research protocols situate control of research with Indigenous communities and partners and prioritize engagement, relationship building and collaboration. Recently, there has been a surge of collaborative and community-based participatory research (CBPR), as well as supporting

literature, to establish considerate, culturally sensitive, relevant and equitable research partnerships that lead to community-owned health strategies and viable benefits to Indigenous communities (Dadich et al. 2019; Kyoon-Achan et al. 2018; Wallerstein and Duran 2006). Such partnerships necessitate good relationships and can help to reverse stereotypes, racism and imbalances of power or privilege; produce knowledge that is meaningful and beneficial to community; enhance self-determination and autonomy; and increase community capacity (Jernigan 2010; Wallerstein and Duran 2010).

Developing Trust Is Key to Developing Good Relationships

In the Nêhiyaw Nations of Maskwacîs, we have been working together for over 10 years as part of a CBPR partnership aimed at improving maternal, child and family well-being (Anand et al. 2018; Oster et al. 2016, 2018, 2021). The goal has always been to attain community-led and entrusted control over research, such that it leads to tangible community benefits. Since the inception of our collaboration, all activities are underpinned by good relationships built upon trust. We acknowledge that every community is unique – as is every project – and thus there is a spectrum of engagement and community involvement. Good relationships will look different for every research project, and pan-Indigenous approaches to relationship building that generalize rather than acknowledge the cultural, linguistic and historical distinctions between Indigenous communities are not appropriate. However, we feel that there are examples from our experience that can be useful for others seeking to collaborate from a place of trusting and respectful relationships.

In our CBPR partnership, hundreds of individuals have been involved over the years. Although the principle of trusting relationships has been front and centre, each relationship is distinct. Here, we briefly describe several key elements that have proven crucial to developing trust between the two of us – researcher and Elder – who, for over a decade, have worked closely together. Once we came together in ceremony, we were able to trust each other fully. Our ceremonial interactions were appropriate for Maskwacîs and our family, and followed the ways of knowing of this territory. The details remain private – suffice to say ceremony is spiritual, healing and connecting. Ceremony permeates all aspects of our research now, and we often come together in this way, specifically to ground ourselves in the spirit, intent and commitment of trusting relationships. In ceremony, our relationship flourishes as we meet in a deeper way by creating a spiritual connection that transcends the western concept of relationship and embraces and imbeds mutual respect, personal vulnerability, compassion and kindness, humbleness, humanness, openness and a responsibility to one another. In ceremony, our relationship becomes more, connecting our hearts rather than our minds. Finally, coming together in ceremony paves the way for ceremonial-based thinking, where we can work together "outside the box" and feel anything is possible.

In order to have a strong relationship, we need to practise humility. Therefore, we consciously decide to come together not as "settler" and "Indigenous," nor as "researcher" and "Elder," but as people in equal partnership. During our time together, we make space

to acknowledge, explore and reconcile the fact that we come from different backgrounds, systems of learning and ways of knowing. We deliberately open up to each other's perspectives and willingly accept that our intrinsic ways of viewing the world are not the only way or the right way. When working together, we move away from an approach to "save the Indigenous person," which seeks to impose western systems and beliefs. Rather, we seek mutual understanding, two-way learning (and sometimes unlearning), equal power dynamics and opportunities to live with and understand each other's experiences. For our relationship, humility ensues when we are our genuine selves, rather than trying to be someone more or different than who we are.

Often, when speaking together publicly, we are asked: "What do trustworthy and respectful relationships look like?" For us, the depth of a meaningful relationship is akin to family. Our families have adopted one another, not from a western or legal sense, but in a real way such that we are and always will be family. We spend time together outside of work to enjoy each other's company, we help and support one another, we see each other at our worst and are still there afterward, we gift each other our favourite things and we do not give up on one another. In short, we are personally and emotionally invested in each other's lives through a relationship that extends beyond the life cycle of a research partnership. Western academia may consider it a risk, but our relationship is our strength and sustains our purpose – research that benefits communities.

Finally, relationships and trust take time. In our experience, trust was not established within the first month, or even year, of our relationship. Now, our entire research framework is centred on relationships. We have learned to go at the pace of the community and individuals involved, allowing them time to navigate their priorities and capacity. We have also learned that relationships cannot be forced into a preconceived and prescribed timeline. Our grant proposals and budgets have been restructured over time to focus on relationships rather than meeting a one-off "checkbox" of activity or as a means to an end. Relationships and trust also take effort, not only to develop, but to maintain and nurture. The effort we put into our relationships extends beyond a standard western working week and requires both flexibility and dedication. It also includes reflection, as well as understanding and acknowledging the value of the knowledge that is being shared.

Conclusion

The cornerstone of effective Indigenous health transformation is, and will continue to be, community-led initiatives based on mutual collaboration as Barnabe et al. (2022) clearly identify. When it comes to transformational Indigenous health research, it is simply not enough to conduct research in a "culturally sensitive way." Researchers must engage in Indigenous methodology where practice is practical, localized and invested, and the focus is on relationships that are emotionally, spiritually, physically and mentally reciprocated. This requires reframing western perspectives and overhauling long-standing institutional barriers such that relationships and trust are at the core of frameworks, processes and programs.

Pan-Indigenous approaches are not the answer as what works in one community may not work elsewhere. Since all communities and projects are unique, we believe that this further reinforces the need to develop good relationships, understand one another and contextualize the research appropriately.

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