“Well-Healthy Relationships”: Using Indigenous Approaches to Support Relationship Formation for Persons with Disabilities

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Abstract. There is limited knowledge about the experiences of intimate relationship formation for those with disabilities, particularly amongst Indigenous populations in urban areas. In order to address this research gap, our project uses an Indigenous approach—talking circles facilitated by a Knowledge Keeper—to engage local community members in discussions about their challenges and journeys of relationship formation, and considerations of community-level efforts at improving socialization and safe meeting spaces for disabled Indigenous persons. Through a central aim of “story-capturing” through semi-structured biographical narratives in talking circles, we demonstrate how Indigenous methods can be appropriately and effectively employed to generate rich qualitative data. Our research also underscores how qualitative Indigenous approaches work to foster an ethical space (Ermine, 2007) between researchers, participants, and their communities, and how this in turn encourages individual and community empowerment.

Keywords: Indigenous knowledge and ways of knowing; interpretive approaches; community-focused research; relationships; disabilities.

1 Introduction

Over the past half-century, there has been increasing recognition within social science research, policy and legal realms, and broader public discourse, of the full personhood of those with disabilities (e.g., Concannon, 2006; Employment and Social Development Canada, 2016). Part of this recognition has involved increased attention to disabled persons’ right to intimate relationships and sexual expression that are “satisfying, safe and pleasurable” (World Health Organization, 2016b). While research exploring the desires and challenges of disabled persons vis-à-vis forming and sustaining intimate relationships remains limited, both studies focused on caregivers’ perspectives (e.g., Hamilton, 2009; Rogers, 2010; Rushbrooke, Murray & Townsend, 2014b; Rueda, Linton & Williams, 2014) and the perspectives and experiences of the disabled (e.g., Hollomotz, 2008; Kelly, Crowley & Hamilton, 2009; Knox & Hickson, 2001; Rushbrooke, Murray & Townsend, 2014a; Tissot, 2009) demonstrate that persons with disabilities strongly desire intimate relationships, but face considerable challenges and feel an overarching lack of control in doing so.

Whereas research on intimate relationships and relationship formation for persons with disabilities is scant, research into intimate relationships amongst disabled Indigenous persons is non-existent, both in our Canadian research context of Saskatoon and beyond. This is particularly troubling given the situation of “triple jeopardy” faced by urban Indigenous persons with disabilities (Durst & Bluechardt, 2001) and suggests that a community needs assessment is warranted that would propel community-driven policy revisions. In the province of Saskatchewan, where our work is based, researchers have noted a public policy vacuum for Indigenous people with disabilities (Durst &
Bluechardt, 2004), problems in their access to services (Durst, 2006; Petten, 2004), cuts to their funding (Charlton, 2016; Craig, 2016), and elevated rates of self-reported disability as compared to non-Indigenous persons (Statistics Canada, 2016; FASD Network, 2016). There is also a striking disconnect between the lack of knowledge about the lived experiences of Indigenous persons with disabilities as they attempt to form intimate relationships and the fact that Saskatchewan’s Minister responsible for First Nations, Métis, and Northern Affairs declared November, 2016 Aboriginal Disability Awareness Month in Saskatchewan (Harpauer, 2016). Further, the Saskatchewan Disability Strategy aims to make Saskatchewan “the best place to live in Canada for persons with disabilities” (Government of Saskatchewan, 2016), yet no research has explored the intersection of indigeneity, disability, and intimate relationship formation in this context.

2 Research Question and Objectives

With the aforementioned lack of knowledge—but awareness of challenges faced by Indigenous persons with disabilities—as our backdrop, our research asks the following central question: What supports and challenges do Indigenous persons in Saskatoon who self-identify as having a disability have as they search for and form intimate relationships? Given that our project follows the participatory action research (PAR) model (see Beeman-Cadwallader, Quigley & Yazzie-Mintz, 2011; Tsey, Patterson, Whiteside, Baird & Baird, 2002), we are working with two community partners, a neighbourhood Indigenous youth co-op and an Indigenous cultural centre, to ask participants a second, fundamental question: Which resources could better provide you, and the Indigenous community in Saskatoon, with support for forming intimate relationships? Following the tenets of PAR in Indigenous research contexts (Kovach, 2009; Menzies, 2001; Romm, 2015; Tuhiwai-Smith, 1999; Wilson, 2008), our research utilizes what OCAP (2016) has stipulated regarding the use of knowledge in the hands of our Indigenous research participants (i.e., participants’ Ownership, Control, Access, and Possession surrounding knowledge).

Concretely, our research objectives are as follows: 1) Conduct a community needs assessment, facilitated by our two community partners, through semi-structured discussions with disabled Indigenous persons in talking circles moderated by a Knowledge Keeper, of existing resources and challenges for those with disabilities seeking intimate relationships. 2) Co-create, with participants, resources to assist in relationship formation. 3) Mobilize knowledge by sharing our findings through academic channels, but most importantly with Indigenous community organizations and populations.

3 Methodology

3.1 Tenets of our Indigenous community-driven research

Using methodologies and methods that promote meaningful discussion and participation when engaging Indigenous communities in research is the overarching framework for our project. This is done to exchange knowledge systems and to holistically address approaches to mental, emotional, physical, and spiritual well-being for participants. Within the framework of this project, we are working with Indigenous participants who self-identify as having a disability, and recognize disability as involving a “complex interaction between features of a person’s body and features of the society in which he or she lives” (World Health Organization, 2016a). In line with Indigenous epistemologies’ celebration of the changing of the seasons, our project involves working to gather data over the course
of a year, and talking circles are geared to a strength-based approach in creating community discussion. Not only do we intend to inform policy through our findings, but also to collaborate with the community to co-create user-friendly resources to assist in the formation of sustainable relationships in the wider community. Indigenous methodologies enrich community involvement more so than standard qualitative research and inspire true knowledge translation.

Our obligation as researchers in an Indigenous-focused project is to go forward in a good way. This involves an expectation of consultation and collaboration with community elders and/or a Knowledge Keeper throughout the research process, consulting with our local tribal council as part of the ethics approval process for the project, and observing proper cultural protocols required in engaging with Indigenous participants—most notably by working to generate findings that they can use for their own benefit and empowerment. Ongoing consent of, and feedback from, participants is held in humble respect by our research team.

What already occurs and has always occurred in our Indigenous communities is provision of access to nourishing environments of social inclusion (see Simard & Blight, 2011). We have always cared for our family and friends living with disabilities and our communities have always come together in friendship and provided safe spaces to meet and form relationships (e.g. through Round Dances, Feasts and Pow Wows). As such, our methodological approach and research methods draw from these traditions while also ensuring rigor and high ethical standards in data collection, analysis, and dissemination.

3.2 Methods

The centrality of trust and relationship-building in sample recruitment.

Establishment of trust is central to Indigenous approaches in social research. Researchers must be accountable not only to participants, but also to participants’ broader communities. It is also paramount that research be guided by an Elder or Knowledge Keeper to ensure that proper cultural protocols are respected throughout research processes. As such, our research began with the establishment of a research team that included a local Knowledge Keeper. The Knowledge Keeper was invited to join the project team by other project members through an offering of tobacco; he accepted the offering of tobacco as an indication of his commitment to offering his guidance. Since he is also a trained social worker, he further indicated willingness to contribute knowledge from his academic background to the project.

Our research team agreed that the most fitting way of recruiting research participants (desired N = 20) would be by building trust and community rapport through a “meet-and-greet” information session at a local community organization which was used to spread the word about the project and to offer an opportunity to meet with the research team. This session was held soon after obtaining ethics board approval for the project. At the meet-and-greet information session, individuals who expressed interest in being research participants were invited to spread the word—through word of mouth and informational flyers—to other potential participants. Thus, the session formed the basis of a subsequent snowball approach to sample building. A target sample size of 20 reflected the exploratory nature of the project, and the desire to focus on gathering detailed life narratives of relationship formation and disability.

Talking circles facilitated by a Knowledge Keeper.
Our Indigenous and PAR approach to research, wherein community and empowerment are central, informed our decision to gather data through a series of small talking circles facilitated by the Knowledge Keeper. Talking circles are similar to focus groups, yet they have a particular emphasis on problem-solving and are intended to provide an opportunity for full emotional openness and disclosure. There is an expectation that participants in talking circles will foster a supportive environment, and that differences in experience and opinion are met with an open heart and mind, but not debated antagonistically. Talking circles require less adherence to structure in discussion than is typical in qualitative interviewing and focus group approaches; the method places more value on the semi-structured exploration of ideas and narratives. Tangents in discussions are not viewed as detracting from the collection of relevant data, but rather as routes toward rich, highly valid data that can point out connections between issues or reveal underlying themes in conversations. As the talking circle facilitator, our Knowledge Keeper thus fulfilled a general moderator role but did not seek to impose much structure on the conversations. Target talking circle sizes were set at 4-6 participants to enable active sharing and considerable opportunity for each participant to speak.

Following cultural protocols, and to recognize that research itself is ceremony (Wilson, 2008), each talking circle began with smudging (i.e., the burning of sacred herbs); the smudging was intended to both cleanse and bless participants and members of the research team present. Talking circles were held at a public, accessible location and the room in which the circles were held was booked for 3 hours each session, with the expectation of built-in breaks at the discretion of the Knowledge Keeper and participants. The research process was designed such that participants were invited to return to a subsequent talking circle if they felt they had additional views to share, and new participants were also welcomed for each new talking circle. This flexibility reflects the Indigenous worldview that research processes must be offered the opportunity to unfold in their own time.

Interpretive approach through “story-catching” and “yarning”.

Talking circles followed an interpretive approach to qualitative data collection and were organized around two complementary Indigenous approaches: “story-catching” and “yarning.” Story-catching, as a broad approach to working with knowledge shared by participants, sees the researchers’ role as that of facilitator and illuminator of participants’ life stories. In keeping with the expectation that a Knowledge Keeper will lend some—but not too much—structure to talking circles, story-catching asks researchers to initiate and validate story-telling from participants, but to leave space for participants to work with (i.e., reflect upon and build on) their stories in collective discussions such as talking circles. Also central to story-catching is a recognition that speaking about one’s life to researchers involves sharing one’s sacred story, and that the vulnerability required to do so is deserving of the researchers’ utmost respect. Yarning, more specifically, involves efforts by researchers to moderate discussions such as talking circles by making and encouraging exploration of links between what participants share. The metaphor, here, is the spinning of a thread (see Bessarab, 2012); as is expected in talking circles, yarning welcomes digressions as fundamental to the development of ideas and themes in discussions. Story-catching and yarning, taken together, are thus inductive, and work forward from participants’ narratives and ideas to generate broader understandings about social phenomena. At the data analysis stage, researchers’ notes from the talking circles were analyzed through a process of thematic analysis (see Braun & Clarke, 2006).

Knowledge mobilization through co-creation of community resources.

Once all data analysis is complete, participants will be invited to re-convene and discuss key themes that emerged during the talking circles. As with the taking circles, this stage of the research process
will be guided by the Knowledge Keeper. Participants will have the opportunity to further discuss key issues and, most importantly, they will discuss with researchers how their identified supports and challenges could be translated into community-level changes for persons with disabilities. Given the intent to fit identified challenges with local solutions, and the PAR approach to research, the research team is open to working with participants toward change in a variety of ways. The direction of this final phase of the research process will not be known until the talking circle participants have reconvened.

**Overarching creation of an “ethical space”.**

The research design, taken together, is intended to foster an ethical space (Ermine, 2007) between researchers, participants, and their communities; this, in turn, encourages individual and community empowerment. Our work is driven by the methodological stance that the challenges faced by Indigenous persons with disabilities cannot be understood, and subsequently addressed, without careful attention to individuals’ sacred stories as revealed through supportive opportunities for story-catch and yarning.

5 **Preliminary findings and further directions**

Discussions in talking circles have thus far emphasized experiences of stigma, lack of affordable community resources, and lack of opportunities for community-building and face-to-face contact for Indigenous persons with disabilities. We look forward to reconvening our talking circle participants to discuss how these findings can be translated into community-level change, and to work toward implementing plans for change.

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**References**


