What's research got to do with it? The Sexy Health Carnival Team Compares *Doing* versus *Evaluating* Community Health Promotion Work

Abstract

The Sexy Health Carnival is a health promotion intervention created by and for Indigenous youth to talk about sexual health and well-being in ways that reduce stigma and are culturally safe. Since the Carnival's inception in 2012, interactive booths, games, and harm reduction supplies have travelled with peer facilitators across Turtle Island to First Nation, Métis, and Inuit cultural gatherings. In 2016, the Carnival teamed up with university researchers to explore its impacts. An iPad evaluation survey was offered to youth Carnival goers over the age of 16 who interacted with project materials and peer facilitators. After the Carnival travelled to 11 gatherings where surveys were gathered, semi-structured interviews were conducted with 10 peer facilitators. Facilitators reflected on how it felt to introduce formal evaluation protocols into their ongoing community outreach work. Interview transcripts were analyzed inductively using NVivo. One emergent theme was the tension that sometimes arose between research and service models. Here we delve into the opportunities and challenges of both approaches and how youth leaders tried to bridge the span Centering the peer facilitator's reflections and advice, considerations are raised for community-based researchers, as well as community members, who may be interested in incorporating research into their grassroots endeavors.

Keywords: evaluation, community outreach, Indigenous peer leadership, cultural gatherings, health promotion

Health fairs are interventions designed to provide educational and medical resources for communities who are marginalised or underserved by the health system (Serina & Giove, 1991; Murray et al., 2014). While health fairs are more common in the United States, they can be found in Canada. Fairs have been critiqued because they are usually staffed by outsiders who enter communities facing layered vulnerabilities without adequate training, sensitivity, and follow-up (Bramante & Song, 2012). There is a growing movement to develop more grassroots approaches to the organisation and subsequent evaluations of health fairs (Ezeonwu & Berkowitz, 2014; Bramante & Song, 2012). The Sexy Health Carnival (hereafter referred to as the Carnival) is an exemplar of such efforts.

The Carnival is a community-developed peer health promotion initiative concerned with delivering sexual health and harm reduction information that is culturally safe for Indigenous youth and their communities. As an offering of love for Indigenous wellbeing, the Carnival draws on the health fair model while attending to its drawbacks through the peer-led design and implementation. It is a fun, interactive series of booths that are instilled with strengths-based, non-shaming approaches to share Indigenous and Western knowledge(s) about sexuality, health, and well-being. The Carnival is composed of a series of handmade booths, featuring information boards, resources (i.e., loot bags, harm reduction materials, pamphlets), fun educational games and prizes and reproductive health samples, including internal and external condoms, dental dams, and lubricant (Figure 1). It is facilitated by peer-trained Indigenous youth to promote conversation and skill building. Since the Carnival's inception in 2012, youth affiliated with the Native Youth Sexual Health Network (NYSHN) have brought the initiative to pow-wows, friendship centers, Métis jig festivals, Inuit gatherings, schools and other community and health promotion events across Turtle Island (or Canada and the United States).

In 2016, the Carnival facilitators partnered with university researchers to evaluate the impact of the Carnival's approach and gain a better understanding of who engaged with the booths across 11 cultural gatherings. When qualitative interviews were conducted with the peer facilitators after the evaluation took place, the theme of transitioning between the role of peer-facilitator to peer-researcher emerged. Evaluating the Carnival's impacts brought challenges and opportunities for the peer-facilitators turned researchers as they sought to build bridges across multiple gulfs — Indigenous and Western worldviews, and community mobilisation versus research paradigms. This paper explores the qualitative reflections of the Indigenous youth peer facilitators and researchers as they navigated the terrain between community engagement and community-based research.

Background

For many Indigenous communities, research remains a dirty word (Tuhwai Smith, 2003). The legacies of exploitative research have cast shadows over researchers and research participants alike, though their weights are unevenly felt. For participants, the harm (whether physical, psychological, spiritual, or cultural; at both individual and community levels) that has been caused by researchers through extractive and exploitative endeavours has led to a rightful distrust in the research process (Mosby, 2013; Robbins, 2006). Indigenous researchers have been responding to dominant methodologies, and research *on* Indigenous peoples (Drawson, Toombs

& Mushquash, 2017), by articulating paradigms that privilege a collaborative approach honouring the constellation of historical, relational, spiritual, communal, and processual knowledges (Wilson, 2008; Absolon, 2010). Indigenous research methodologies are distinct, complex, diverse, and context dependent (McGregor, Restoule & Johnston, 2018; Absolon, 2010). Nevertheless, an Indigenous research paradigm situates knowledge "as belonging to the cosmos of which we are a part and where researchers are only the interpreters of this knowledge" (Wilson, 2008, p. 38). From this orientation, relationship, relationality, sovereignty, and self-determination are central tenants (McGregor, Restoule & Johnston, 2018; Wilson, 2008; Hart, 2001).

Compatibility can be observed between community-based participatory research (CBPR) and Indigenous research approaches (Koster, Baccar & Lemelin, 2012; Drawson, Toombs & Mushquash 2017; Ferreira & Gendron 2011). Core CBPR principals include co-learning and partnership, capacity building, sharing, and applying findings with research partners, and investing in long-term partnerships (Minkler, 2004; Wallerstein & Duran, 2010). Community-based health promotion initiatives co-developed with Indigenous youth and researchers, where principles of Ownership, Control, Access, and Possession (OCAP) were central, are examples of where community-based research and Indigenous ways of knowing have successfully met (Monchalin et al., 2016a; Flicker et al., 2019a; Flicker et al., 2019b). However, careful attention to process is vital for success. CBPR methods are neither inherently safer nor more ethical for Indigenous peoples (Flicker et al, 2007) due to the absence of relational accountability— a central principle in Indigenous methodologies (Wilson, 2008). For instance, this absence can manifest in a spectrum of participation and ownership over the research project or having Indigenous knowledges (inadvertently) misused (Laveaux & Christopher, 2009; Lavallée, 2009; McGregor, Restoule & Johnston, 2018; Menzies, 2001).

Indigenous researchers who develop research relationships with their communities have written about the tensions that can arise. For instance, researchers have noted a fractured sense of identity between the university and their communities, how the hierarchies of 'researchers' and 'researched' impact data collection, and issues associated with navigating accountability within academic and community worlds (Srigley & Varley, 2018; Whetung & Wakefield, 2018). Lynn Lavallée (2009) details the challenges that came with upholding cultural protocols during the ethical review stage of her research. These included advocating to have an Elder on her doctoral dissertation committee, and subsequently, needing to develop a curriculum vitae to legitimise his 70 years of experience and knowledge. Dilemmas such as these have propelled Indigenous researchers to share their research stories in ways that resist conventional academic constraints. For instance, using oral/storytelling writing styles, drawing on culturally relevant frameworks (such as the medicine wheel, Trickster stories, or languages), or grounding their work in land-based pedagogies are some of the ways that Indigenous researchers are contributing to and reviving Indigenous research paradigms (McGregor, Restoule & Johnston, 2018; Wilson, 2008; Todd, 2016; Drawson, Toombs, & Mushquash, 2017; Absolon, 2010).

The relationship between the worlds of research and community driven work can sometimes surface a 'clashing of […] cultures' (Guta, Flicker, & Roche, 2013, 446). Findings drawn from interviews with community partners and peer researchers in CBPR projects have shown the

institutional policies of funding bodies and human resource protocols are at times, in opposition to community values, needs, and processes (Guta, Flicker, & Roche 2013; Castleden, Sloan Morgan, & Lamb, 2012; Nichols et al., 2013; Menzies, 2001; Loseto et al., 2020; Minkler. 2004). For example, Flicker (2018) reflects on the layered challenges in conducting research in culturally responsive ways with Indigenous Elders within bureaucratic requirements, such as honoraria payment. As Flicker (2018) details,

> Some of the folks we were working with had been violently hurt by the state (through the residential school system) and actively tried to avoid engagement with it. They considered it insulting for us to ask for SIN [Social Insurance Numbers] or status cards in exchange for cultural teachings. (p. 317-318).

Other noted tensions between research and community partnerships include divergent project timelines, the scales of urgency regarding action and on the ground outcomes, as well as the question of genuine community involvement and participation (Nichols et al., 2013; Travers et al., 2013; Minkler, 2004; Loseto et al., 2020; Menzies, 2001). Across studies, authors agree that implementing the theoretical principles of CBPR methods can be a tangled process; fostering relationships underpinned by open and transparent communication and taking action to make visible the power imbalances are pathways to unknotting (though not dissolving) these dilemmas (Minkler, 2004; Nichols et al., 2013; Castleden, Sloan Morgan, & Lamb, 2012; Guta, Flicker, & Roche, 2013). In this paper, we respond and add to the chorus of the dilemmas and lessons learned when intertwining community engagement and community-based research by sharing the voices of the Carnival's peer facilitators.

Methods

The Carnival was developed as an educational offering of the Native Youth Sexual Health Network (NYSHN), a grassroots organisation working to address issues of sexual health, community rights, and justice, that is by and for Indigenous youth. In 2012, Alexa, a youth facilitator at NYSHN came up with the idea of creating a supportive environment for her community to learn about sexual health, reproduction, and well-being in fun, destigmatising, and culturally informed ways (Lesperance, 2016). Today, the Carnival is one of NYSHN's most popular offerings, with approximately 100-200 requests/year. In 2014, a pilot study was launched in partnership with York University to understand the feasibility of bringing sexual health interventions into cultural spaces and assess the Carnival's relevance and effectiveness with Indigenous youth (Monchalin et al., 2016b). Dr. Renée Monchalin (who was then a Métis graduate student of Sarah's and affiliated with NYSHN) spearheaded the analysis as part of her Master's work. The Carnival was met with great enthusiasm: 99% of survey respondents said that they would return to the Carnival, and 96% felt that pow wows were a good place to talk about sexual health and HIV (Monchalin et al., 2016b). The pilot study laid the groundwork for securing additional funding to launch a comprehensive evaluation spanning diverse cultural, territorial, and geographic locations (Mikinnaakominis: Taking the Sexy Health Carnival across Turtle Island, 2016).

In 2016, the Carnival received a three-year grant from the Canadian Institutes for Health Research to attend eleven cultural gatherings— six First Nations, three Métis, and two Inuit events – and evaluate the impacts on attendees and facilitators. The project received ethics approval from York University's Research Ethics Board. The research partnership was rooted in an eight-year relationship between Alexa, NYSHN, and Sarah Flicker, an allied settler scholar at York University. Alexa was a principal investigator alongside Sarah. Community permissions included: partnering with youth leaders and community organizations known to NYSHN and providing cultural adaptations where applicable. Community permissions for the Carnival were obtained via vendor application forms from the gatherings. These gatherings were selected because they were each large, multi-day events that attracted sizable crowds from surrounding regions. To evaluate the Carnival, youth were encouraged to engage with the booths and then complete a short survey. The survey was developed by NYSHN youth leaders and researchers and administered on iPads. Indigenous youth who were between 16-25 (in alignment with NYSHN's definition of youth) who interacted with the Carnival for at least five minutes, and who were able to speak and understand English were invited to participate. Upon survey completion, youth were given a $5 gift certificate. The survey gauged young people's willingness to return to the Carnival, their opinion on having sexual health interventions at cultural gatherings, their intentions to engage in sexual activities and/or drug use, their sexual and drug use history, as well as their demographic information. The quantitative data that was collected is reflected upon elsewhere (Monchalin et al., forthcoming). At each event, there were at least three peer facilitators from NYSHN who were responsible for the set-up, engaging Carnival attendees, and administering the survey.

Following the eleven gatherings, semi-structured telephone interviews were conducted with ten peer facilitators to better understand their experience doing health outreach at Indigenous gatherings and their perceptions of the overall response to the Carnival. Interviews were conducted by two of Sarah's undergraduate students, one of whom later became a Carnival facilitator. Interviews lasted between 30-90 minutes. They were transcribed verbatim and inductively coded in NVivo (Thomas, 2006) by Caterina (Tess), a master's student of Sarah. Some facilitators opted to use their real names; others chose pseudonyms. Summaries of the themes were compiled by Tess and shared with the peer facilitators at a two-day retreat at York University in December 2019. During this "member checking," peers provided their insights on preliminary findings and engaged in analysis discussions (Harvey, 2015). Facilitators added, revised, and clarified the initial themes and summaries drafted by Tess. Facilitators reflected on the peer programming (NYSHN et al., forthcoming), and what it was like to bring the Carnival to cultural gatherings (NYSHN et al., 2022). Here, we share their reflections on what it was like to transition between being a peer-facilitator for a grassroots intervention to being a peer-researcher for the Carnival. Tess and Sarah drafted the paper and circulated it to the team for feedback. Final approval was given in May 2021.

Findings

Facilitators reflected on the challenges and opportunities that came with weaving a research evaluation into the facilitation of the Carnival. Because the Carnival was a grassroots intervention before it was a research project, most facilitators had experience facilitating in

research and non-research settings. Nine facilitators had both settings to compare and contrast, while one facilitator only had experience facilitating the Carnival while the research was underway.

Challenges

A shared observation between facilitators was the challenges that came with the formal survey administration. Many described that it was difficult to maintain an organic conversation with Carnival attendees while screening for survey eligibility. Alexa remarked that "we [had] to sort of guess people's age 'cause you know you have to be 16 to do the survey". For Tina, this was frustrating because there were instances where people outside of the age restrictions were engaging with the Carnival:

> younger folks and older folks who were very interested and who spent maybe like three hours hanging around and playing games and engaging in the content. And one on one, I could definitely ask them and talk with them about what their experience was that day, but it's hard not to have their voice included in the research aspect.

Eligibility and "guessing" also extended to Indigenous identity in some cases. Simone reflected on an event that took place at a university in Alaska with nursing and high school students: she felt uncertainty about directly asking people's identity because "you want people to feel welcome." When it was time to transition to the technical requirements and the eligibility parameters of the survey, facilitators felt that it interrupted the flow of conversation.

The survey was, at times, difficult to oversee and administer on top of day-to-day facilitation duties. When Madison was responsible for the survey, she couldn't do as much facilitating because she was "behind the scenes gathering youth to do our survey. [… the] focus [becomes] get[ting] the surveys done and not as much, talking and hanging out with youth." Alexa reiterates this point where the Carnival "takes up a lot of energy, actually […] facilitating hundreds of people [… It's] mini workshops really, like tons of them within twelve-hour[s] and doing [them] three days in a row. You know, it's very time consuming." Keeping track of gift card distribution and the iPads felt like an additional burdensome responsibility on top of the peer-facilitators' many roles.

The exasperation that facilitators at times felt extended to a larger critique of academic knowledge systems, where Alexa noted: "it takes a lot of dumb data and research to like prove things that we already inherently know in our communities." Many of the facilitators were equally frustrated by the need to have to "prove" or "make the case" through these formalized procedures when they felt they already had an excellent handle on the needs in their communities.

Opportunities

While the survey and the ethical formalities of research protocols present some limitations, several important benefits to the facilitators, NYSHN, and wider audiences were also identified. While Alexa voiced her concerns, she also emphasised that,

> we aren't just doing the surveys because we need to for the research— we also see value in answering those questions because we're wanting to make links about how sexual health prevention is very much linked to culture, and culture is a protective factor.

Facilitators understood that research findings can lend support and legitimacy to calls for change. Some facilitators remarked on how the research allowed for richer conversations with youth. Madison said that the survey is a "great vehicle to talk about some of the issues that we talk about all the time. So, let's say on the survey someone needs some clarification on […] a term that's used […] we can use that as an avenue" to explain concepts. Having the additional survey component to the Carnival can act as another means for education and conversation. Shane described that the gatherings included in the research were longer and larger than some of the other settings where the Carnival has travelled. They remarked that having an extended presence at a gathering can help with the de-stigmatization of sexual health—

> One of the strengths and gifts of [the Carnival] as a part of the research is that it has allowed that time for community to engage with it in a way that's appropriate for them at any given time. Versus, when you get invited in to do something like, for two hours. You can talk about the content and those things, but you can't have the depth of conversations or relationships that you have when you can do something for a longer period of time.

The research provided the benefit of extending the capacity and reach of the Carnival. While NYSHN and the Carnival team may want to go to communities where there are passionate and engaged youth, it is not always possible due to financial limitations. Tina explained that the research funding has allowed the team "to be more creative around going to communities that maybe otherwise wouldn't be able to budget the money it takes to ship the Carnival." The research funding also provided the resources to fairly compensate the facilitators for their work and allowed the Carnival to be brought to communities that would not otherwise have the opportunity. The infusion of a steady stream of dependable resources over a three-year period was widely identified as an important and wonderful part of being engaged in research.

Tips for Success

Considering that research is contested terrain among many Indigenous communities, facilitators all emphasised that centering the leadership of Indigenous youth is the 'best avenue' to health promotion and research efforts. As Alexa described, she values Indigenous youth because "their expertise [… is] more valuable to the work we do, because they're invested in it." Alexa continued to say that Indigenous youth "are such a beehive of knowledge [with] inherent knowledge." Shane extends this sentiment— where having culturally relevant materials provided by Indigenous peer leaders is "the most effective part" because in sharing health promotion "from your heart, people [will] relate." Finding supportive research partners who, as Krysta put it, would "support local Indigenous people or Indigenous youth to be involved, hopefully in a

paid way, to direct and decide what those activities will look like so that it can be consensual, it can be culturally safe" was vital. Finding like-minded community partners was also recommended by facilitators. As Simone articulated, sometimes "the work might already be underway" and in connecting with a network of people on the ground, "they can let you know the background of what is already going on in that community […] so that you're actually adding something that's useful and not just something that you think everyone should know."

In terms of the research materials themselves, Iehente raised the important consideration of accessibility for people of differing ages and abilities— "for some, it was like, really long survey and they were like, 'fuck this, I'm not finishing it.' Especially places where the literacy level is lower." In a related vein, Clara said that it was sometimes difficult to "get somebody to stay an extra 10 minutes for a research purpose" and it took some "creative discussion around reminding people the importance of feedback on community tools and that we want to improve our own services." This assessment can offer insight into the design or the framing of the research instruments. All facilitators mentioned the positive community response to the interactive and engaging aspects of the Carnival. Finding ways to make the research portion even more engaging might likely benefit response rates.

Discussion

Researching the Sexy Health Carnival presented the peer facilitators with both challenges and opportunities. The predominant challenge raised was organizing and administering the survey; namely making sure that potential participants were eligible and interrupting the informal flow of conversation to solicit participation. These experiences reflect concerns raised by other Indigenous researchers working with their own communities who have reflected on how the process of collecting research data can impede relationships (Sgirgly & Varley, 2018; Leddy, 2010). Carnival facilitators' experiences of introducing the iPad survey into their dynamics with participants echoes the reflections of Autumn Varley who described how the presence of a voice recorder "managed to hinder trust and negatively impact relationships." (Sgirgly & Varley, 2018, 53). While most participants liked the iPads, the introduction of any formalised technologies and procedures into a space that is meant to be safe and welcoming presents an inherent challenge (Sgirgly & Varley, 2018).

Facilitators also voiced frustrations regarding the need to legitimize what Indigenous communities already instinctually know about sexual health through academic conventions. In Western culture, legitimacy is awarded only when something is formally and empirically observed (Akena, 2012). The critique of what knowledge is and what ways of knowing are legitimate are well documented (Hart, 2010; Lavallée, 2009; Tuhwai Smith, 2003; McGregor, Restoule & Johnston, 2018). The facilitators of the Carnival add to this chorus. They understand that gathering data through the survey is double edged: on the one hand, they strategically understand that academic legitimacy provides particular kinds of power than can be leveraged towards health equity aims, on the other, they chafe and resist the institutional structures that uphold this dynamic that perpetuates damage-centered narratives (Tuck, 2009).
There is growing recognition (inside and outside of academia) to ensure that projects and programming are developed, designed, and implemented in tandem with the intended communities. Nevertheless, this form of 'inclusion' does not always translate into equitable

compensation. As Feige and Choubak (2019) describe people with lived experience often are underpaid or expected to volunteer due to both organisational limitations as well as the systemic prevalence of 'adultism'— a broader set of stereotypes and biases that diminish young people on the basis that they are inexperienced, incompetent, or naïve (de la Fuente-Núñez et al., 2021). These inequities in pay, and the undermining of their expertise was underscored as a challenge by the peer facilitators. The peer-facilitators articulated the requirement for any research and community partnership to ensure peers are compensated in dignified and equitable ways for the gifts and experience they bring. Engaging in research brought many material benefits to the NYSHN team including steady stable salary funding for facilitating staff over a three-year period and the ability to expand outreach efforts. While financial resources are desperately needed by small grassroots organizations, funding agreements should center the self-determination and agency of community partners, whereby community groups can direct the funds as they see fit. Feige and Choubak (2019) present solutions where organisations can fundraise with local governments, or businesses, as well as building peer compensation into funding applications.

The collaboration between the Carnival and university researchers was successful due to the relational trust and commitment that was fostered over eight years. Alexa, as the co-creator of the Carnival, was a principal investigator alongside Sarah; a concrete way to ensure that the research unfolded with community control. Similar to Travers and colleagues' (2013) work with the TRANS Pulse project, the Carnival was a community offering first, and a research project second; establishing teams made up of community members is one way to begin restoring the power imbalances that can be inherent within research dynamics. This does not dissolve questions of power and tension, rather, new dilemmas are introduced. For instance, while principal investigators may have more influence and voice in the direction of the project, they are not always compensated for their time, while other project members do not have the same decision-making powers (Travers et al., 2013). As Flicker (2018) described, to address community partners' needs, there needs to be careful, creative, and strategic consideration to modify traditional approaches and advocate for these modifications within departments, faculties, and ethics committees. Redressing tensions that arise within CBPR projects might have researchers taking a more scenic, winding route, but it is done in the vision of both actualising CBPR goals, and more importantly, so community partners can continue engaging their communities in meaningful and transformative ways.

Limitations

This was a small qualitative study that engaged a limited group of facilitators who were all part of facilitating and evaluating the same intervention. The Sexy Health Carnival is an intervention that is designed by the youth that facilitated it and share similar views to one another. Care needs to be taken around generalizing to other contexts. Nevertheless, the insights around opportunities, challenges and tips around grassroots research evaluation may be applicable to other contexts.

Conclusion

In *As We Have Always Done* (2017), Leanne Simpson writes: "it is not [by] happenstance or luck that Indigenous peoples and lands still exist after centuries of attack. This is our strategic

brilliance" (6). Community engagement that stems from needs observed and felt are key contributors to shifting inequities, though their significance is understated in community research. Developing partnerships that center support and community resurgence and decolonizing goals can be a pathway to effecting powerful change. As more Indigenous communities begin to lead their own health promotion efforts (Allen et al., 2020; Flicker et al., 2019a; Whitty-Rogers et al., 2020), care will need to be taken between balancing research and implementation needs to ensure the benefits are most widespread.

Acknowledgements

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