Developing an FASD Health Promotion Social Media Campaign Using Community-Based Participatory Peer Review: Notes From Atlantic Canada

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Abstract

Introduction: Health promotion awareness activities by health agencies, such as those by the Public Health Agency of Canada, aim to increase health literacy, often using social media campaigns to reach large audiences. Objectives: The objective of this research was to explore how community peer-reviewed social media content can facilitate the reach of health promotion campaigns, with specific regard to awareness around fetal alcohol spectrum disorder (FASD), alcohol, and pregnancy in Atlantic Canada. Methods: We developed a health promotion social media campaign consisting of 16 digital posters, then implemented a community-based participatory peer-review process to request input and feedback from individuals with lived experiences, caregivers, professionals who work with individuals with FASD, and various advocates for FASD throughout Atlantic Canada. Reviewer comments were then directly applied to update poster content, which was redistributed for secondary approval before circulation on Facebook and Instagram. Results: Reviewer feedback was constructive, with various suggestions for updates being applied to images and text choices. Once posted, the health promotion campaign was well received and reached over half a million viewers across the two platforms in the first three months. Engagement and interactions were overall positive, with minimal negative responses and only one post flagged by the platform as a social issue advertisement. Discussion/Conclusion: With the inclusion of diverse voices from the FASD community in the co-creation of the content, we argue that the campaign's style, messaging, and language more accurately reflected the intended audiences and was made accessible to a wider demographic, thus strengthening awareness and prevention messages. We explore a health promotion social media campaign development process, providing valuable
examples of how to encourage and create more safe spaces that promote open conversations about health and gradually dismantle outdated ideas and systems so we can begin addressing stigma by delivering accurate, non-judgmental health information.

Keywords: health promotion, social media, fetal alcohol spectrum disorder, Atlantic Canada

Introduction

Health promotion is a key mechanism for educating the general public about issues and topics related to individual and societal health. With the expansion of social media in recent years, digital health promotion campaigns are now being launched online to reach broader and more diverse audiences than previously available. In this paper, we highlight literature on health promotion and the role of the Public Health Agency of Canada (PHAC) in these initiatives. We provide an example for discussion: the development of a social media campaign created for and by Atlantic Canadians around fetal alcohol spectrum disorder (FASD), alcohol, and pregnancy, and addressing associated stigma. In describing the development of a digital prevention and awareness social media campaign, we discuss implementing a community peer-review process to solicit input and feedback from individuals with lived experiences and various advocates and champions for FASD in Atlantic Canada. We argue that the campaign was strengthened and made more accessible by including these diverse voices. Finally, we discuss the implications of community peer review as a framework that can be engaged by organizations and working groups aiming to develop health promotion campaigns, as well as the importance of such campaigns regarding FASD prevention, awareness, and stigma reduction and their relevance in Atlantic Canada.

Literature Review

Health Promotion and FASD

Health promotion has been identified as a key area of public health. The use of health promotion and awareness activities is intended to broaden individual understanding of health-related information and is commonly state-sponsored (Epp, 1986). Health promotion activities and tools include posters, pamphlets, radio, television, and social media ads, and have been developed to educate the public about the potential harms of substance use and related practices—such as alcohol and tobacco use—and the importance of safe sex practices, among other topics. Health promotion is an important theoretical and practical theme worth reflection and examination: according to the participants of the 6th Global Conference on Health Promotion, health promotion is a “process of enabling people to increase control over their health and its determinants, and thereby improve their health” (The Bangkok charter for health promotion in a globalized world, 2005, p. 10). During the COVID-19 pandemic, more people moved many of their daily activities online, including health-information seeking and service accessing. As an enduring result, much of what we began, and are still, consuming and learning is accessed through online platforms and sources. However, health promotion activities have been critiqued for individualizing health practices and outcomes and overlooking socio-economic factors and social exclusion as contributors to health issues and mortality rates (Hankivsky & Christoffersen, 2008; Raphael et al., 2008). Online campaigns in
particular are restricted, as they require internet and/or social media access and user knowledge to benefit from these types of messages; this technology-based exclusion can impact persons living in rural and remote regions in Canada, which disproportionately impacts Indigenous communities (Canadian Radio-television and Telecommunications Commission, 2019). Still, as these inequities have become magnified through the COVID-19 pandemic and access to the internet has been expanding, health promotion remains and will likely become a more and more useful mechanism for increasing health literacy among the general population; this has also been successfully demonstrated in other regions with high internet access and use among Indigenous communities (Heffler et al., 2019).

In Canada, PHAC is the federal government agency responsible for public health, and health promotion is among its initiatives. As part of this work, PHAC is the national lead on FASD prevention and the improvement of outcomes of individuals affected (PHAC, 2014). FASD is a lifelong neurodevelopmental disability impacting individuals’ brains and bodies among those exposed to alcohol before birth (Cook et al., 2016). FASD is a health promotion issue unparalleled in complexity due to social drinking practices, stigma, myths, and misunderstandings about alcohol both generally and during pregnancy (Choate & Badry, 2019; Dej, 2011; Greaves & Poole, 2005). Prevalence estimates indicate that approximately 4% of Canada’s general population has FASD, a leading cause of developmental disability in the country (Popova et al., 2019), which translates to over 96,000 people in the Atlantic provinces based on 2021 Census data (Statistics Canada, 2022).

As demonstrated through widespread research across various disciplines (Comack, 2018; Nathoo et al., 2013; Rutman & Hubberstey, 2020), individuals use alcohol and, in some cases or instances, consume alcohol at high levels, for a multitude of complex and intersecting reasons: this can include everything from dealing with the strains of poverty and unemployment, coping with trauma from historical and/or ongoing experiences of abuse and family violence, or navigating feelings of loneliness and isolation, among other increasingly common stressors and strains (PHAC, 2016; Rutman & Hubberstey, 2020). These factors typically result from larger societal issues, including systemic inequities, thereby increasing the complexity of alcohol consumption during pregnancy. Individuals who consume alcohol may commence or cease doing so at various life stages, including during pregnancy. Many of the above strains and stressors can increase someone’s likelihood of continuing to drink during pregnancy (Greaves & Poole, 2005; Roche et al., 2015). Although there is no timing or amount of alcohol that has been found safe to consume during pregnancy, there continue to prevail many myths about the effects of alcohol on our bodies and on a developing fetus, combined with myths about alcohol and addiction (Drabble et al., 2011; Poole & Greaves, 2013; Stewart, 2016). It is thus critical that social media campaigns and awareness and prevention efforts are trauma-informed, culturally appropriate, and also take into account their own potential role in perpetuating any ideas, images, or symbols of stigma and/or shame, not only around alcohol but any themes, due to any unconscious biases or inadvertent oversights.

A multi-pronged approach that takes social determinants of health into account is necessary to effectively address FASD, and prevention is an essential component of such work. Work by Poole (2008) for PHAC outlined a four-part FASD prevention model under which various activities and services can be undertaken. The multi-level prevention framework has been widely implemented and discussed since its conception (Hubberstey et al., 2019; Poole et al., 2016; Thomas et al., 2014). The first level of the prevention model is broad awareness, which informs our current approach
and refers to campaigns and other promotional strategies supporting the health of people who can become pregnant. Further, Poole (2008) outlines level-one activities benefitting and engaging the broader community. The type of information included in level-one activities should provide information to the general public about alcohol and health, including risks associated with alcohol during pregnancy; provide information about where additional information and support can be found; and encourage and promote the community to be active supporters of healthy pregnancies and FASD prevention (Hubberstey et al., 2019; Poole, 2008; Rutman & Hubberstey, 2020).

**FASD and Atlantic Canada**

In Atlantic Canada, FASD awareness and prevention work has long been championed through community-level work, such as efforts led by family resource centres and advocates across the region. Work has accelerated in recent years with an Atlantic FASD conference held in Nova Scotia in 2017, the formation of the Atlantic FASD Community Network in 2020, and core funding and policy action enacted by provincial governments (Dunbar Winsor & Morton Ninomiya, 2018; Dunbar Winsor & Ward, 2022; Government of Newfoundland and Labrador, 2022). Further, needs assessment research began in 2021 in Newfoundland and Labrador and has now expanded into Nova Scotia, Prince Edward Island, and New Brunswick to include all four Atlantic provinces (Dunbar Winsor & Ward, 2022; also see fasdNL, n.d.). Yet, despite these advancements in Atlantic Canada, FASD remains underdiagnosed and under-resourced. In particular, families and individuals impacted by and/or diagnosed with FASD experience a lack of resources and support (Dunbar Winsor, 2020).

In 2021, fasdNL, a pan-provincial FASD organization in Newfoundland and Labrador and lead of the Atlantic FASD Community Network, was awarded funding by PHAC’s FASD National Strategic Projects Fund for a three-year Atlantic-wide project titled Toward Prevention: An Atlantic FASD Awareness and Collaborative Action-Building Initiative (Public Health Agency of Canada, 2021). The main focus of this project is the promotion of awareness about FASD and alcohol use during pregnancy, dispelling common myths about the diagnosis and prevention of FASD. In this paper, we discuss in detail the co-development and release of one of the project’s deliverables: a social media campaign aimed at increasing FASD prevention and awareness across the four Atlantic provinces, using sponsored social media images that have been reviewed by FASD “experts,” which for our current research purposes refers to individuals living with FASD and/or caregivers and community-based professionals working with individuals diagnosed with and/or impacted by FASD.

**Methods**

Community-based participatory research (CBPR) is an approach implemented in health promotion research designed to improve the health of various populations by connecting researchers with communities and sharing knowledge in partnership (Jull et al., 2017; Viswanathan, 2004). CBPR encourages the co-creation of knowledge between researchers and community members in a way intended to minimize potential harms and improve the accuracy and accessibility of health information being shared (Hacker, 2013; Israel et al., 2005; Jull et al., 2017; Wallerstein & Duran, 2010). CBPR revolves around teamwork and aims to include the community, researchers, and representatives at all points during a research project, from the development of the question to research dissemination (Hanson & Weber, 2018; Montag et al., 2017). We utilized CBPR to inform the development of the social media campaign and as a mechanism of centring place-based knowledge from Atlantic Canada. This approach was accomplished through a convenience
sample of individuals with lived and “expert” experiences recruited by email, and it provided feedback that fundamentally shaped the development of the campaign.

Researcher Positionalities

Research positionality and the social location of individuals warrants acknowledgement and discussion (McCorkel & Myers, 2003; Rice, 2009). We approached the development of this campaign and the community-based participatory peer review process with recognition and appreciation for collaborative input and dialogue about the campaign. We engage in FASD work and research—and this project specifically—as white settlers, feminists, and individuals with various years of community, academic, and lived experience. Our community work centres lived experiences around FASD through dialogue, organization governance, and supportive approaches and resources. These identities shape how we interact with this work and research and how we view our contribution as strengthened by meaningfully including the contributions of others through community-based participatory peer review (McCorkel & Myers, 2003).

Drafting the Campaign and Community-Based Participatory Peer Review

The decision to conduct a community-based participatory peer review for this campaign was driven by several factors and included logistical challenges. First, FASD is a stigmatizing topic; we wanted to create a respectful process whereby the wisdom of community members is adequately represented (Corrigan et al., 2019). The project was initiated following consultation with and/or feedback from community members where a need for prevention material was established, and was inherently designed to feature community feedback throughout, recruiting community members who are seen as FASD “experts” in various capacities to be involved. The final campaign images were shared with these experts for approval before being shared publicly and widely in various formats and languages, to make them as accessible and equitable as possible. This chosen process aligns with the use of CBPR (Hacker, 2013; Israel et al., 2005; Jull et al., 2017; Wallerstein & Duran, 2010), specifically when working with populations who may be stigmatized (Corrigan et al., 2019; Wallerstein & Duran, 2010).

The CBPR approach is also a valuable method in research and work involving Indigenous communities; our awareness and prevention campaign was guided by the Truth and Reconciliation Commission of Canada’s (TRCC; 2015) final report call to action #33, asking for federal, provincial, and territorial governments to recognize the need to address and prevent FASD in collaboration with Indigenous groups. This call to action was a critical focus for this campaign, which is also informed by and follows the eight evidence-based tenets (as applicable for our campaign and continued health promotion work), to guide the creation of community-based, cultural-led FASD prevention programs in Indigenous communities (see also in Wolfson et al., 2019); these programs were co-developed based on the perspectives shared by diverse Indigenous and non-Indigenous participants, and reflect Indigenous values and beliefs and practices around health and wellness. One primary goal with this approach and the resulting awareness and prevention campaign was to build a stronger understanding of how long-standing colonial practices and systems of education and health have led to gaps in Indigenous health promotion, based on direct input from Indigenous and non-Indigenous persons and groups. A further aim was to ensure our messaging avoided negative messaging that perpetuates alcohol, pregnancy, FASD, and/or cultural myths, reproducing stigma, shame, and poorer health access and outcomes.
By providing an opportunity for community-based participation, we sought meaningful input and feedback from individuals personally impacted by FASD (see Burgess-Proctor, 2015; Green & Mercer, 2001; Jull et al., 2017). We involved a diverse group of individuals within Atlantic Canada who either live with FASD, have been engaged in FASD work in various capacities, or are seen as “experts” in the FASD community. We invited these individuals to be transparent and open about the campaign development and to create a campaign in which individuals, groups, and communities recognized themselves via representation in the images and text (Israel et al., 2005). Finally, we aimed to create a versatile campaign that can be used in various contexts and by many different groups across Atlantic Canada in the future.

A key goal of the campaign development was to ensure that individuals in the community had an opportunity to review and provide feedback before its release. Accordingly, individuals and organizations were identified and invited via email using the community organizations’ respective email contact lists to review the drafted campaign images and text. Organizations included project partners Kids First Association, Mi’kmaq Family Resource Centre, NB FASD Centre of Excellence, Daybreak Parent Child Centre, and Exploits Valley Community Coalition. Further individuals included Indigenous Elders and young people, parents and caregivers of individuals with FASD, people with FASD, and community service providers who work with individuals with FASD.

Social Media Campaign Development

The overarching goal of the social media campaign was to develop and deliver accurate information about FASD, alcohol, and pregnancy through sponsored posts on Facebook and Instagram as part of the PHAC Toward Prevention Atlantic Canada project (2021–24). Campaign development focused on diversity among the individuals portrayed in the campaign images. For example, images were chosen to show same-sex partners, multi-generational families, gender- and racially-diverse individuals, Indigenous people, and connections to the land. Additional goals of the campaign included showcasing southern and Northern contexts and providing meaningful examples about supporting healthy pregnancies that were partner and community-focused, thereby not placing responsibility solely on pregnant people. Research from Australia that explored the use of social media–based health promotion among Indigenous people found that, although most examined approaches have generally focused on behavioural and not structural health promotion and prevention (Stark et al., 2022), approaches that centred on cultivating strong, supportive online communities (effectively fostering the development and/or growth of social capital) appeared to have a more pronounced positive effect on users’ information-sharing practices compared to those that commonly rely on more aggressive, blame-based, and emotion-inducing approaches often employed in alcohol and smoking mass media campaigns (Hefler et al., 2019). It is important to note that the main target audience of the campaign was not specifically Indigenous individuals but individuals with FASD, including individuals who may identify as Indigenous. This is another reason we chose CBPR, as it is frequently used in health promotion research including Indigenous populations (Gonzales et al., 2021; Montag et al., 2017), and we made sure to seek out and include feedback from Indigenous individuals.

Each digital campaign poster was accompanied by text about FASD prevention or awareness. Font and colour (e.g., predominantly dark background colour with lighter font colour) were chosen based on accessibility best practices for ease of reading and viewing, alongside using CamelCase (capitalizing the first letter of each word) for hashtags (Garcia-Cabot et al., 2015; Government of Canada, 2022;
Princeton University, 2022). The campaign seeks to adopt an inclusive, representative, strength-based approach that avoids stigmatizing, blame-based, or otherwise harmful messaging about alcohol use—both generally and during pregnancy especially—and FASD. Both scholarly/academic (e.g., peer-reviewed publications) and grey literature (e.g., government and organizational reports, academic institutions) were used to identify and select “best practices” to include in the campaign. The campaign development began by identifying key messages related to the prevalence of FASD, its underdiagnosis, ways to provide tangible support during pregnancy, and the benefits of implementing strategies to support individuals with FASD. In the following discussion, we address how we integrated best practices into various campaign development and release components.

Peer Review Feedback

In total, 29 individuals were invited to provide feedback. Of those invited, 17 were from Newfoundland and Labrador as a result of the organization leading the project being located in this province and the campaign being reviewed internally by fasdNL’s board of directors (composed of 12 individuals at the time of review). Three people were invited from Prince Edward Island, five from Nova Scotia, and four from New Brunswick. Twenty-two people from the Atlantic provinces reviewed the campaign and provided their feedback. Despite knowing who had been invited to provide feedback, the online form into which reviewers entered their feedback afforded them anonymity in their responses. Thus, we did not track how many reviewers resided in each Atlantic province.

The feedback comments ranged from minor (e.g., advising against the use of italics) to more significant (e.g., language choice). In addition, there were instances in which campaign images solicited polarizing responses from reviewers. For example, the digital poster showing a young white mother with tattoos received negative feedback (e.g., “hate the tattoos”) and also positive feedback (e.g., “I love this picture”). The project/research team read, discussed, and addressed all peer-review feedback. Most of the feedback was integrated into the final version of the campaign, although in some cases the project team ultimately decided to keep the original content despite a minor feedback comment that had suggested change. The revised campaign was then recirculated to partner individuals and organizations for the second round of feedback. Finally, following community peer-review approval, the campaign was translated into French, Inuktitut, and Mi’kmaq.

Final Campaign and Dissemination

The final development of a thoughtful, long-lasting campaign required the creation of 16 digital posters, each delivering evidence-based and non-stigmatizing messaging about alcohol, pregnancy, and FASD. Four digital posters were launched on Facebook and Instagram as sponsored posts targeting individuals 18+ in the Atlantic provinces for eight-week periods in both English and French. Following the eight weeks of posts circulated, a two-week break was observed, and another set of four digital posters was launched. fasdNL, the project’s lead organization, was responsible for launching and rotating the campaign posters.

Ensuring that we had created an inclusive social media campaign for the four Atlantic provinces (Newfoundland and Labrador, Nova Scotia, Prince Edward Island, and New Brunswick) also required translating English material into some of the various languages spoken across the region, including French, Inuktitut, and Mi’kmaq. As part of the response to the TRCC’s (2015) Calls to Action, specifically around language and culture as well as health (see, for example, calls 13, 18, 19), our work can begin to acknowledge and gradually start addressing the racism that has been
impacting the health of Indigenous peoples in Canada, including Atlantic Canada, as a result of colonization. These significant impacts have been demonstrated in not only our health care systems and settings but also in FASD work (from prevention to diagnostics to supports) that has often linked this diagnosis to Indigenous communities in dangerous ways. This claimed link, however, is not based on any current empirical evidence and is instead a racist outcome of these systems and models that have negatively impacted the health outcomes and lives of any individual who is suspected to be impacted by and/or has been diagnosed with FASD, and this has been particularly harmful to Indigenous communities and the re-traumatization and shaming of Indigenous peoples in Canada.

Social media was chosen as the avenue of campaign delivery over print-based options for several reasons, including its ability to target a wide age range of individuals living in Atlantic Canada, its usefulness for gauging the reach of the campaign over time, and its accessibility in rural and urban areas as well as remote parts of Atlantic Canada. For example, on Labrador’s north coast, cell phone service is virtually unavailable, so residents and visitors rely heavily on Wi-Fi and the Facebook Messenger app to communicate with one another. More broadly, Facebook has become used by many different users and is no longer considered a social media site only for young people as it was in its early years (Pew Research Center, 2021). As a result, social media has become an increasingly helpful tool for health promotion campaign delivery, despite it not being used or accessible universally. To reach broader audiences, including individuals who do not have consistent internet access or do not use social media, a radio ad campaign was also developed and aired on radio stations across Atlantic Canada.

Limitations of digital health promotion campaigns mean that some groups (e.g., older adults or those who do not use social media) and regions (e.g., areas in rural, remote, or Northern contexts without regular access to the internet) may not view the campaign. However, the creation and release of a corresponding radio ad campaign helped to mitigate this limitation. Additional limitations included the lack of alt text for individuals with visual impairments to accompany the campaign in its initial launch. This will be included in subsequent campaign rotations during the ongoing PHAC-funded project.

**Discussion**

**Lessons from Campaign Development and Community-Based Participatory Peer Review**

The FASD health promotion social media campaign was launched in December 2021 and is ongoing until 2024 through sponsored posts on Facebook and Instagram (see Figures 1, 2, and 3 for digital poster examples). The campaign targets individuals aged 18 to 65 living in Atlantic Canada and has been positively received thus far, as measured by online comments and feedback from community members and partners. The campaign's reach has extended to over half a million Atlantic Canadians in the first three months following its launch. Our use of community-based participatory research through a peer review process was to create a campaign that could have a greater and wider impact on the communities it intends to serve—all communities in Atlantic Canada—than had we not used such an approach. The added focus on sociologically, culturally informed and structural factors (see Wolfson et al., 2019), which are still often overlooked in much of the published work coming from other disciplines in health prevention and promotion (e.g., medicine, health care, psychology), can also assist in its reach and impact and in recognizing the TRCC’s Calls to Action.
In addition to the successes, there have also been unexpected challenges. For example, Facebook’s sponsored posts go through a review period before publishing, and one of the digital campaign posters was denied in English only because it was flagged as being an advertisement about “social issues.” The poster read thus: “Nearly half of Canadian pregnancies are unplanned. Communication and birth control can help prevent unintended pregnancies.” Despite the message being accurate as based on Canadian data and approved by community peer-review partners, the sponsored post was still rejected after filing for a review. Despite some challenges and limitations for access, social media awareness campaigns remain an important, accessible venue for health promotion due to the ability to reach rural, urban, remote, and Northern locations as well as a wide age range of viewers, particularly during the COVID-19 pandemic when many in-person activities were suspended. Further, health promotion campaigns delivered through social media allow readers to learn more about health-related topics, improving their health literacy around topics such as alcohol and pregnancy with the added ability and privacy to access additional information and resources online.

As outlined by Poole (2008), level-one prevention work is part of the diverse and multi-layered work required to prevent FASD and to support people who can become pregnant with safe alcohol use, pregnancy, and health literacy more broadly. Therefore, in developing this campaign, we sought to expand level-one prevention work by developing a health promotion that is supportive of everyone’s health collectively and from a community public health approach that includes gender and sexual identities with an emphasis on pregnant people’s health.

The next steps include measuring the uptake of the campaign through survey delivery to evaluate the campaign’s reach across sectors and regions. Added benefits of such an evaluation survey will provide additional information on the benefits, limitations, and overall impressions of social media as an avenue for health promotion.
Figure 2
FASD Digital Campaign Poster in Inuktitut

Note. A digital campaign poster presented in Inuktitut reads, “Partners, friends and family can support healthy pregnancies with alcohol-free activities. Consider taking a walk, watching a movie, or making arts and crafts.” The image shows the importance of connection to the land relevant to Indigenous and non-Indigenous contexts and offers suggestions for indoor and outdoor alcohol-free activities.

Figure 3
FASD Digital Campaign Poster in French

Note. A digital campaign poster presented in French reads, “Nearly half of Canadian pregnancies are not planned. Communication and birth control can help prevent unplanned pregnancies.” The image shows a diverse group of young adults socializing (a demographic for increased alcohol consumption). It underlines the importance of communication and birth control practices as a shared responsibility.
The community-based participatory peer-review process that was used to develop the campaign provides a framework to address important questions in the development and circulation of health promotion campaigns and materials. For example: who is represented in the campaign images, what type of language is used or not used and the influence of literacy, who has an opportunity to provide meaningful input, and how research and knowledge translation and mobilization activities can remain equitable and accessible to individuals and communities.

Conclusion

The Atlantic-wide social media campaign discussed here is intended to address FASD prevention and awareness with a strength-based approach supported by evidence and community members. This campaign aims to address the stigma associated with FASD by promoting public awareness and delivering accurate and consistent information by reframing alcohol use during pregnancy to include partners, friends, and family members. Moreover, in doing so, it highlights how partners, families, and communities can support healthy pregnancies rather than placing the responsibility on pregnant people alone.

As described in this paper, developing an FASD prevention and awareness campaign for social media highlights opportunities to improve awareness and understanding about complex, sensitive, and stigmatized topics such as alcohol and pregnancy. The use of community peer review provided opportunities to engage individuals with lived experience and communities in developing health promotion materials. Further, in doing so, the act of highlighting community voices through review and input helped ensure individuals’ and organizations’ voices are represented and heard.

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