Community Voices in Program Development: The Wisdom of Individuals With Incarceration Experience

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ABSTRACT

Objectives: This health promotion project used participatory processes to engage all stakeholders to design and pilot preventive health tools in partnership with and for individuals with incarceration experience. This article outlines the methods of engaging with this marginalized population and interventions conducted to successfully utilize participation in the planning phases of the project to develop collaborative values, mission, and project scope.

Participants: Eighteen men and women with incarceration experience participated through two community organizations that were invited to work as project partners.

Setting: Participatory planning was conducted through an iterative process and partnership between an academic institution and community organizations.

Intervention: Engagement was developed through community networks and partnership building, including articulation of shared values and formation of a Project Advisory Committee. Participatory planning was facilitated through focus groups and interviews conducted with prison leavers to narrow the scope of the project to three health priority areas. Discussion analysis was conducted using interpretive phenomenological qualitative methodology to extract themes in terms of underlying systemic barriers to health and suggestions for ways to address them.

Outcomes: The interventions resulted in collaborative project planning and allowed for the prioritization of promoting holistic health for individuals with incarceration experience in mental health and addiction, cancer, and blood-borne infectious diseases by sharing knowledge, supporting self-advocacy, and strengthening relationships.

Discussion: Community engagement and participatory processes allowed the project to be more relevant to those it serves, and also meaningfully engaged prison leavers in an empowering participatory process to address health inequities.

Key words: Community-based participatory research; prisoners; community health planning

La traduction du résumé se trouve à la fin de l'article.

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The Canadian incarceration rate of 116 per 100,000 people reveals a relatively high rate of incarceration compared to Western European countries.[1] Although the absolute number of Canadians with incarceration experience is relatively small, they experience many health inequities and are among the most underserved populations in Canada.[2-5] Furthermore, there is increasing evidence that the determinants of criminality and recidivism are similar to the determinants of health. For example, criminal behaviour patterns are associated with substance dependence which is often an expression of trauma and unmet health and social needs, including inaccessible health care services.[6] Imprisonment itself also negatively impacts health for several reasons, including separation from family, unhygienic facilities, and poor self-care as a reaction to imprisonment.[7] Self-reported health problems are also found to increase with inmates' duration of incarceration.[8] Upon release from prison, individuals face many challenges to reintegration, including social exclusion, which is often underpinned by the stigma of incarceration.[5,9,10]

Although health-seeking behaviours of prisoners can improve when appropriate prison health services are provided, barriers persist to accessing health services in the community.[11] As health care provision often focuses finite resources on the most pressing health needs, individuals with incarceration experience in particular have little access to preventive health programs. Indeed, the authors of the current article were unable to locate any Canadian-based preventive health promotion programs targeted to individuals with incarceration experience living in the community.

The Collaborating Centre for Prison Health and Education (CCPHE) at the University of British Columbia is committed to using participatory processes of engagement in order to

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Figure 1. Project values

Values

Partnership
Equal participation of all relevant stakeholders

Voice
All partners are encouraged to share their opinions and ideas

Active Listening
Truly hearing what each other have to say

Respect
Acknowledging that everyone has something to offer

Reciprocal Learning
Learning from one another's strengths

Cultural Safety
No judgement

Transparency
Honesty and accountability in all actions

encourage collaborative opportunities for health, education, research, service and advocacy to enhance the (re)integration of individuals who have been in custody into their families and their communities. Participatory modes of engagement are derived from participatory action research (PAR), which recognizes the need for persons being studied to participate in all phases of research to foster empowerment, community capacity building, and social change.[12,13] In recognizing that health concerns are value-laden and culturally defined,[13] the academic group acknowledges that prison health interventions are more likely to be effective with input from those with incarceration experience.

In 2005-7, a participatory health research program in a female correctional centre enabled incarcerated women to identify their health goals.[14] In follow-up, a CIHR-funded participatory research project is investigating barriers and facilitators to attaining health goals. Preliminary findings from this project suggest that effective preventive health tools can assist women in attaining their health goals following release from prison.

This article focuses on a CCPHE community-based preventive health project funded by the Vancouver Foundation that aims to develop preventive health tools using participatory approaches with individuals with incarceration experience. The objectives of this article are 1) to describe the processes by which the project engaged individuals with incarceration experience as partners in all phases of the development of the project, and 2) to describe the processes by which the preventive health priorities were decided.

PARTICIPANTS, SETTING AND INTERVENTION

Participants

The academic research team invited two organizations, both networks of prison leavers in British Columbia, to be partners in the project: Long Term Inmates Now in the Community (L.I.N.C.) and Women in2 Healing (Wi2H). L.I.N.C. is a registered society that comprises mostly men who have served long prison sentences.[15] Wi2H is an informal network of women with incarceration experience in the provincial corrections system which provides closed Facebook support and opportunities for women to engage in participatory health and education activities.[16] Both organizations have the ability to disseminate invitations to others, inviting participation in the project beyond their formal membership to reach wider networks of formerly incarcerated men and women living in the province.

Figure 2. Project partnerships

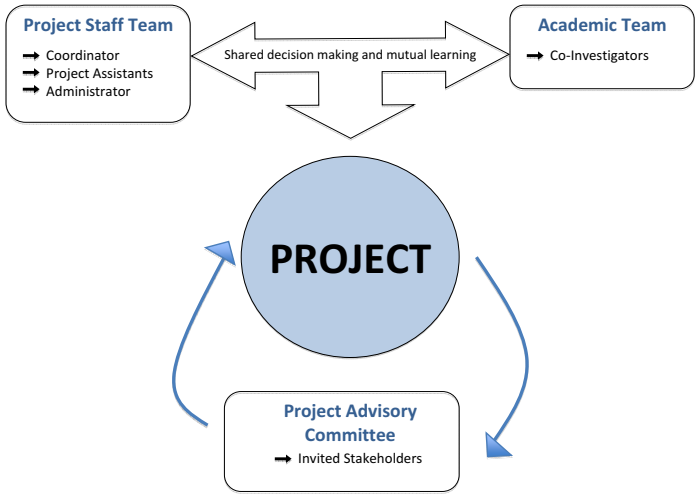
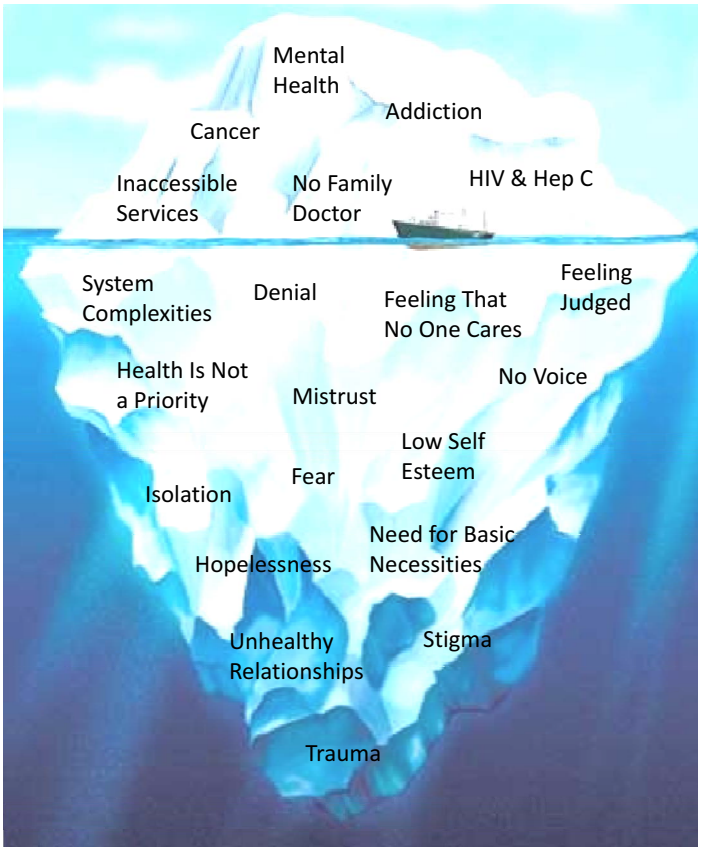


Figure 3. Iceberg analogy of prison leavers' health priorities with underlying causes



Setting

In this participatory project, the setting is within an iterative process that aims to design and pilot-test preventive health tools and programs through engagement of individuals with incarceration experiences who are living in British Columbia, Canada. An example of the iterative nature is in the funding proposal, where the details could not be articulated because the design of the intervention required input from participants who were not yet engaged in directing that content. As such, the

Table 1. Representative Quotations From Participant Prison Leavers to Illustrate Themes and Subthemes

Share Knowledge	
"Knowledge is power to a person"; "It's about education"	
Mentorship and Peer Education	"If I had somebody who I knew went through everything that I went through it would be more inspiring." "It's by telling our own stories."
Mutual Learning	"It's equal sharing of information."
Support Self-Advocacy	
"Her experience taught me to push and push… and not stop pushing."	
System Complexities	"Most people who get out of jail have no idea that they need a medical card." "Those guys trying to get disability, it's straight up hell."
Judgement and Stigmatization	"It's supposed to be safe, nonjudgemental… and healthcare providers are not that way." "When they found out I had been in prison, it's like a switch went off." "People have that fear of being judged or being criticized for their lifestyle choices."
Empowerment	"Who is going to listen to me? I'm just a goddamn drug addict and a criminal." "Then when they make decisions for themselves, they're empowered." "People just coming out of prison aren't confident."
Strengthen Relationships	
"Having people who love me, and people who I love…"	
Trust	"They don't trust doctors. There's been no reason to trust them." "It's being open, and building trust."
Hope	"When people are feeling hopeless, how are they supposed to know what a health goal is?" "I wouldn't give a shit about my health if I didn't have hopes and dreams for my future."
Connections	"There is something different about having someone to chat with and another human being there." "It would be helpful to have somebody, a contact person." "People sharing hope and their experience of how they broke the cycle."

setting is continually changing and dynamic, requiring flexibility in project design, management and participation.

Intervention

Engagement of Individuals With Incarceration Experience as Equal Partners in All Phases of Developing the Project

In order to reach the project's objective of engaging individuals with incarceration experience as equal partners in all phases of project development, relationships were initiated at the very onset of the project. Members of Wi2H and L.I.N.C. were invited to assist in reviewing the letter of intent and the grant proposal application. The academic research team then invited representatives of both organizations to an initial meeting to develop a set of values that would underpin the project, and to begin a dialogue regarding the preventive health topics that the project would focus on. After funding was awarded, ethics approval was obtained from the University of British Columbia's behavioural research ethics board. The academic research team invited stakeholder organizations (and their representatives) to collaborate in the Project Advisory Committee.

Processes by Which the Topics for Preventive Health Were Decided

The project aims were to improve the health outcomes of individuals with incarceration experience through user-designed preventive health tools and programs. In the funding proposal, we explained that the three preventive health priorities would be chosen in an iterative and participatory manner. Key informants from both partner organizations were invited to participate in focus groups to assist in identifying the priority foci. Two separate focus groups were planned in partnership with the organizations' facilitators and a research assistant (O'Gorman), and were conducted at regularly scheduled member meetings in the respective organizations' meeting places in the lower mainland of British Columbia. Participants were invited through e-mail and a closed Facebook group and were provided gift card honorariums for their contribution to the project. Three key informant in-depth individual interviews were also conducted with women who expressed interest. They were invited to participate through snowball sampling via e-mail invitation.

The first focus group with L.I.N.C. was comprised of 12 men with a total lifetime in custody averaging 21 years, and 4 female family members who were present for the discussion but did not participate. Age ranged from 23-68 years, with an average of 47 years; 1 participant was Aboriginal and the rest were Anglo-Canadian. The second focus group with Wi2H members was comprised of 3 women with a total time in custody averaging 5 years and an average age of 40 years; 1 participant was Aboriginal and 2 were Anglo-Canadian.

Focus groups and interviews were recorded and transcribed verbatim, then analyzed using Interpretive Phenomenological Analysis (IPA). The purpose of IPA is to describe how individuals experience and interpret a phenomenon, in this case health. Findings were member-checked with focus group participants, and were then presented, discussed and verified during the initial meeting of the Project Advisory Committee (PAC). Findings were distributed to all participants in a literacy-appropriate information sheet, which included contact information to facilitate feedback or questions regarding the interpretation process. These activities ensured that findings were validated by and communicated with participants, acknowledging that their contributions were essential to the project.

RESULTS

Engagement of individuals with incarceration experience as equal partners in all phases of the project development

At the first formal meeting of the PAC, the list of project values was discussed and agreed upon (see Figure 1), the conceptual diagram for the project decision-making processes was developed (see Figure 2), and the PAC terms of reference were finalized. The

meeting also included a time of self-reflection for all PAC members modeled on Aboriginal talking circles.

Processes by which the topics for preventive health were decided

Based on the literature and previous prison health research findings, the co-investigators had conceptualized three potential topics of preventive health that were disease-focused. However, thematic findings extended beyond a disease focus to encompass more humanistic issues deemed as underpinning a variety of common afflictions and issues impacting people with incarceration experience. Similar to an iceberg analogy (Figure 3), the determinants of poor outcomes in the health priority areas of cancer, mental health and addiction, and blood-borne infectious diseases were visible (and perhaps measurable), yet deeper issues underpinned health challenges for prison leavers, many of which reflect the social determinants of health. For example, health care access was described as a challenge, as a male participant confirmed, "most people who get out of jail have no idea that they need a medical card." Expanding upon this, a female participant expressed feelings of disempowerment in asserting, "who is going to listen to me? I'm just a goddamn drug addict and a criminal."

Although much of the focus group and interview discussions centered on issues and barriers, there were several suggestions for ways to deliver health promotion programs. The subthemes of these ideas and their justifications were clustered into the themes of: share knowledge, support self-advocacy, and strengthen relationships, as outlined in Table 1.

These findings led to the formation of the project mission statement that was formalized at the PAC meeting: "Promoting holistic health and preventive practices for individuals with incarceration experience in mental health and addictions, cancer, and blood-borne infectious diseases by sharing knowledge, supporting self-advocacy, and strengthening relationships." The findings enabled the project mission statement and interventions to include a biopsychosocial definition of health, and to assure that future project directions address disease outcomes as well as their underlying social factors.

DISCUSSION

Innovative in design and partner engagement, our project demonstrates the feasibility and importance of using participatory methods in preventive health projects, especially within design and priority setting with a marginalized population. The results of the focus groups and interviews indicate the high level of self-awareness that prison leavers possess, despite facing many barriers to health. Through participatory action research methodologies, the focus of the project shifted from medical topics to a more holistic approach that aims to address the social determinants of health. By addressing these large structural inequities that exist "below the surface", the project is likely to have more sustainable and wide-reaching impacts. Additionally, involving participants in the planning phases of a project acknowledges their lived experience and communicates its value. In working within community-identified areas for intervention, this project becomes more meaningful to the population it serves by emerging from and being responsive to the end-users' needs.

The importance of participation in the planning phases is outlined in several health promotion theories. In the PRECEDE-PROCEED model, understanding health from the perspective of community members is poised as a pragmatic and moral imperative. Participation is also highlighted as an important part of sustainability and capacity building.[13] Fournier and Potvin (1995) identify three goals of public participation with different underlying values: 1) maximizing the outcomes of a program, 2) acting as a democratic tool to empower marginalized people, and 3) helping people take control of their lives.[17] It is amid this tripartite of motivations that voice, empowerment, and capacity building reveal participation as an intervention in and of itself. The process, therefore, is as important as the findings that are drawn from the data.

One major challenge faced in this intervention was assuring accessible participation. For example, 16 women expressed interest in attending the Wi2H focus group, but only 3 were able to attend. Invitations to participate in phone interviews were therefore distributed in order to allow for participation with fewer barriers. In the future, project meetings and workshops may need to include an option for conference-call participation or take place in a more accessible location. A potential challenge for this project with so many stakeholders will be to maintain the focus and direction of the project as consistent with the values and mission that were developed by those it serves.

Despite these challenges and the significant time investment that is required, this intervention demonstrates that health promotion projects must engage end-users from the outset, especially in project planning. While generalizability is neither the aim nor claim of qualitative research, the findings drawn from this pilot project afford important direction for future work. Specifically, longitudinal studies comprising formative feedback from end-users along with measurable program outcome evaluations will assist programs to more effectively support these underserved populations.

Through the participatory planning process, not only do programs become more relevant to those they serve, but community members also become engaged and empowered. The depth of knowledge revealed in focus groups and interviews with prison leavers confirms the value of emic perspectives in thoughtfully considering the care needs of this population. Future projects, therefore, especially with marginalized populations, must make a concerted effort to involve those they seek to serve, and to trust their wisdom.

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RÉSUMÉ

Objectifs : Notre projet de promotion de la santé a fait appel à des processus participatifs pour amener tous les acteurs à concevoir et à mettre à l'essai des outils de prévention pour les ex-détenus, en partenariat avec ces personnes. Nous présentons les méthodes employées pour mobiliser cette population marginalisée et les interventions menées pour utiliser leur participation avec succès au stade de la planification du projet en vue de définir les valeurs de collaboration, la mission et la portée du projet.

Participants : Dix-huit ex-détenus, hommes et femmes, ont participé au projet par l'entremise de deux organismes communautaires invités à devenir partenaires du projet.

Contexte : La planification participative s'est déroulée selon un processus itératif et à l'aide d'un partenariat entre un établissement d'enseignement supérieur et des organismes communautaires.

Intervention : La mobilisation s'est faite par les réseaux communautaires et l'édification de partenariats, notamment en énonçant des valeurs partagées et en créant un comité consultatif pour le projet. La planification participative a été facilitée par des groupes de discussion et des entrevues menées avec des ex-détenus pour limiter la portée du projet à trois aspects de la santé jugés prioritaires. Les discussions ont été analysées selon une méthode qualitative/interprétative phénoménologique pour en extraire les thèmes du point de vue des obstacles systémiques sous-jacents à la santé et des moyens suggérés pour les aborder.

Résultats : Les interventions ont mené à la planification concertée du projet et permis de cibler en priorité la promotion de la santé holistique des ex-détenus dans trois domaines : la santé mentale et la toxicomanie; le cancer; et les maladies infectieuses véhiculées par le sang; pour cela on a utilisé le partage des connaissances, l'appui à l'autonomie sociale et le renforcement des liens.

Discussion : La mobilisation communautaire et les processus participatifs ont permis au projet d'être plus pertinent pour ses bénéficiaires; le projet a aussi impliqué de façon constructive des ex-détenus dans un processus participatif habilitant afin d'aborder les iniquités en santé.

Mots clés : recherche participative communautaire; prisonnier; planification en santé communautaire