



A Critical Examination of Experiential Knowledge in Illicit Substance Use Research and Policy

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Abstract

This paper examines the role of experiential user group knowledge in the development of substance use research, policy, and programming. Specifically drawing on themes contained within the sociology of knowledge and Marxist conflict theory, it is argued that the inclusion of experiential persons and collectivities is necessary to produce socially and culturally grounded knowledge regarding the meaning and consequences of illicit substance use. We argue that knowledge flowing from the everyday existence and experiences of drug users forms the basis of *effective* policy and programming. Experiential knowledge challenges "expert" groups such as policy makers and academic researchers to be reflexive about their position vis-à-vis those they study and to develop effective alliances with user groups. In addition to informing research, policy and programming, user group organizations play a key role in challenging dominant rhetoric regarding illicit drug use as a social problem and demonstrate that the most marginalized members of society can effectively mobilize in the interest of emancipatory social change. Despite the important benefits associated with the inclusion of experiential persons and user groups in research and various levels of social policy and programming, many structural and cultural barriers to meaningful inclusion of user groups exist; it is important to identify these barriers so that they can be strategically engaged and overcome. Two Canadian examples of user group organizations are discussed in order to illustrate both the positive influence and common challenges associated with including experiential knowledge and user group organizations in policy and program development.

Keywords: Substance use; Sociological theory; Marginalized communities; Social justice; Experiential knowledge

Introduction

Drawing on the example of illicit substance user-groups, this paper presents an overview of the importance of experiential knowledge to research, policy, programming and capacity building among marginalized [1] communities. An *experiential person* is someone who has direct personal, lived experience of a phenomenon, either presently or in their past. The experiential persons' movement can be broadly categorized as a form of identity politics to the extent that it has most commonly been used by persons representing behavioral (drug use), physical (disability, HIV/AIDS), and historical (youth in government care) backgrounds. Experiential groups bear many of the same characteristics of classic identity-based interest groups such as women, persons of specific race, and persons of particular sexual identities; what these groups have in common is that, a socially constructed identity, in particular a discriminated and oppressed identity-becomes the basis for organizing and for solidarity [2]. Experiential groups, perhaps even more strongly than other types of identity-based groups, are further characterized by their strong belief that firsthand experience produces unique, privileged knowledge, which should form the basis of the development, design and delivery of programs and services designed to address the needs of their membership.

The epistemological assumptions associated with experiential groups - namely the idea that, from experience comes unique knowledge, are supported by several social theories. Broadly speaking, one of the basic tenets of Marxist and Neo-Marxist theory is that the oppressed, due to their structural position in the economic mode of production, have a keener understanding of a more just society and are therefore pivotal to social change. Similarly, feminist standpoint theorists have long argued that experience, specifically the experience of gender oppression in the context of patriarchy, allows women to perceive structural and cultural facets of society that are often overlooked by men. Women are thought to be more keenly aware

of relations of dominance in society because these are incongruent with female gender roles. In addition, Durkheim's ideas, which were advanced in the late sixties by Berger and Luckman, are also instructive as they direct attention to the way knowledge is situational, a product of specific historical and social conditions and the interactions between groups and individuals [3,4]. While this line of thinking differs from the Marxist and standpoint feminist ideas outlined above in that it is not an argument for epistemic privilege per se, it does support the idea of experiential knowledge to the extent that it argues against objective, universal knowledge. It directs our attention to the interests and powers that support specific knowledge(s) over others when different groups interact. These basic ideas, and others which will be explored below, provide a theoretical framework for understanding the epistemic privilege claimed by experiential persons and groups. However, Neo-Marxist works, specifically the ideas of Gramsci [5] and the theoretical rifts that have plagued second and third wave feminism, are also instructive and foretell enduring challenges among experiential groups. For example, as will be discussed below, hegemony - the coordination of principles of thought into coherent ideology - and essentialism - the notion of a distinct ontological nature - are also social theoretical concepts which help us to understand the limited impact of experiential groups on social policy as well as the difficulties they

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experience maintaining solidarity and framing claims for inclusion in the context of potentially heterogeneous memberships [5-7].

Drawing sometimes explicitly on the theoretical ideas presented above and their associated methodological models, and at other times, on pragmatic social concerns, several contemporary models for the inclusion of experiential groups have emerged in academic, community non-profit, and government environments. Three of these models are presented below: (a) community-academic partnership (including participatory action research); (b) transformative community practice and (c) liberation theology. Much of the work conducted by experiential groups, specifically in the non-profit sector and by government organizations is done in the absence of a specific guiding model, but these models are nevertheless important to look at comparatively because they highlight how the practice of experiential involvement includes a necessary distribution of power between various stakeholders, resulting in vastly different outcomes. Each of these models also contains ideas regarding the objectives, challenges and best practices of experiential participation, and a topic that is also presented in greater detail later in the paper. For example, in addition to having to confront hegemony and essentialism, user groups often must form alliances with individuals and groups having “outsider” or “non-experiential” status. The experiential involvement models discussed below all address this topic with different ideas regarding how such relationships should be developed and managed. Similarly, the task of maintaining funding also poses problems for experiential groups as they often find themselves shifting the framing of their objectives to suit the requirements of funding bodies, a task which is becoming increasingly difficult for organizations representing marginalized populations in the context of neo-liberalism and retrenchment of welfare state funding.

Following the discussion of contemporary experiential involvement models, two examples of experiential groups are outlined: the Canadian National Coalition of Experiential Women (CNCEW) and the Vancouver Area Network of Drug Users. While these organizations have been challenged by many of the pitfalls of experiential politics noted throughout this paper, they also illustrate very clearly the important role played by experiential groups in the context of substance use policy and widespread discrimination against drug users, reminding us that no amount of research or expertise can replace lived experience [8]. The importance of the experiential voice of drug users is particularly important given the widespread acceptance of drug users as either menaces to society, irreparably “sick,” and the seemingly intractable notion that the solution to the drug use “problem” is social control [9,10]. The paper concludes with ideas for improving experiential participation in the context of illicit drug use groups and presents ideas for further inquiry.

Theoretical Framework: Experience, Epistemic Privilege and Social Change

The idea that oppressed persons have access to special knowledge or that experience is the foundation of knowledge is well supported in social theory. Contemporary Marxist, feminist and social constructionist paradigms suggest that experiential groups are not only the key to knowledge production, but that they also have a unique role in social change, albeit the emphases in each of these bodies of theory differ as do their concepts of desirable social change. One of the most influential arguments for the inclusion of oppressed groups comes from Marx [11]. Marx proposed that the proletariat or working class were better able to understand the contradictions in society because of their oppressed position and involvement in physical labour as opposed to capital accumulation [11]. Marx believed that the proletariat’s insights

regarding the contradictions of capitalism would create unrest and eventually leads to the downfall of capitalism [11]. Importantly, Marx believed that the working class did not possess a sense of social justice inherently, but rather gained it through collective organizing, which raised consciousness of their historical position vis-à-vis the capitalist class. Although this is a crude representation of Marx’s theory of class relations and social change, what is fundamental to this paper is that Marx argued that oppression leads to epistemic privilege and the organizing of oppressed persons was the basis of social change.

As everyone knows, the downfall of capitalism did not occur as Marx expected and, in fact, capitalism not only expanded but went on to develop new forms with a more global reach. Seeking, in part, to explain why the inevitable revolution that Marx envisioned did not come to pass, contemporary Neo-Marxist theorists further developed two concepts which are also key to understanding the experience of oppressed persons in knowledge production and social change: hegemony and false consciousness. The concept of hegemony is most widely associated with the work of Gramsci [5] and Laclau and Mouffe [6] who broadly conceived of it as political and social power flowing not from economic dominance or force, but rather from the coordination of intellectual and moral ideas into a culture of knowledge, within which the values and ideas of dominant culture become “common sense.” Coupled with the material disadvantage that often accompanies subordinated or discriminated identities, hegemony of knowledge and ideas pose an additional barrier to marginalized groups who seek to redefine the systems of meaning and thought that gird material deprivation. These processes function to offer them up as sites of social repudiation, surveillance, and other forms of social control. In the case of drug using populations, ideas regarding decriminalization, drug use as pleasure, and “drug users” as contributing citizens have been virtually impossible to advance as the discourse mainly shifts between sin and sickness models, which at worst are associated with stringent social control and at best are associated with more liberal concerns of harm reduction and problem management. Hegemony also works in more subtle ways and not only governs dominant tropes and discourses of drug use, but also determines the manner in which knowledge must be presented if it is to be considered. Thus, ideas regarding what constitutes valid knowledge may be inextricably linked to the maintenance of class and other forms of oppression; so while user groups may be invited to present ideas arising from their live experiences, these ideas are likely to be subordinated to existing knowledge frameworks or dismissed if they are not congruent with dominant expertise. In addition, the terms, conditions, and formats under which knowledge can be presented are also likely to be governed by dominant interests, thereby adding a further barrier to marginalized populations’ ability to make their ideas and knowledge public. Further, as the term false consciousness refers to, hegemony also has a silencing effect on marginalized or minority populations as they often not only accept the terms of meaning and knowledge creation of the dominant intellectual and governing class, they may also actively seek to uphold them rather than revolting against them. The concept of hegemony, as will be shown below, helps to explain why experiential or user groups, despite widespread acceptance within many mainstream academic and policy oriented environments, often fail to impact significant change on the mode of knowledge production and, in some cases, even align in broad strokes with the very views that give rise to discrimination. For example, peer-based treatment movements such as Alcoholics Anonymous have long advocated a view of the *addict* as an ontological other, using this view as a basis of solidarity and a motivation for lifelong recovery; while these ideas have been useful within the context of recovery discourse, as many experiential persons will attest to, they also reify the same discourse

that has implicated the deep social stigmas surrounding addicts as lesser and dangerous members of society.

Gramsci felt that it was imperative that an education system that would foster the development of working class (or minority group) intellectuals was necessary in order to challenge hegemony [5]. Paulo Freire further developed his ideas regarding education of the oppressed in his work on the culture of silence and critical pedagogy [12]. Influenced by Marxist ideas regarding hegemony and false consciousness, Freire elaborated on what he called a “culture of silence” among oppressed groups [12]. According to Freire, alienated and oppressed people are not heard by the dominant members of society and find themselves immersed in the language and ideas of dominant society through the education system and other governing institutions of society such as the media [12]. Within this context, the alternative ideas of oppressed people are not advanced and, in fact, oppressed groups and individuals may find themselves internalizing the ideas and images of dominant society and relying on dominant notions of governance as discussed above. Freire’s solution to the culture of silence was his concept of critical pedagogy, which aimed to raise the consciousness of oppressed groups using a method that encouraged students to question and challenge the ideas about their own experience and social position [13].

In sum, Marxist and Neo Marxist ideas as exemplified by Gramsci and Freire support contemporary claims regarding the epistemic privilege of oppressed persons and experience as the basis of social change, but they also contain warnings regarding the difficulty of disrupting the hegemony of knowledge, which will be instructive as we consider the contradictions inherent in the mainstreaming of experiential or user group participation in academic and policy oriented circles. Also influenced by Marxist and Neo Marxist theory, feminist standpoint theory is perhaps the most relevant theoretical framework for considering the value of experience to knowledge production because it spans both identity and economic-oriented politics and has therefore, alongside race theory, become a model for the proliferation of identity based interest groups [14,15]. The inclusion of women in academia is a key example of an oppressed group redefining the standards of knowledge and producing knowledge “by women and for women,” emerging in direct opposition to male dominance of the terms and practices of knowledge production [16]. Feminist standpoint theory claims an epistemic privilege over the character of gender relations, and of social and psychological phenomena in which gender is implicated, on behalf of the standpoint of women [16].

Exemplifying their Marxist roots, proponents of feminist standpoint theory see critical consciousness emerging from the experiences of a group of persons rather than from individuals. Thus, women’s collective experiences of oppression become the point of departure for an alternative knowledge grounded in everyday experience of subjugation. Again, drawing on Marxist theory, standpoint feminists argue that women’s subordination directs them to uncover relations of ruling rather than mask or naturalize them; they develop a double consciousness wherein they are simultaneously aware of the dominant relations of ruling, but at the same time they can clearly see how these relations are incongruent with their own experience and a source of oppression.

Feminist standpoint theory, however, has also been criticized with respect to two issues that are germane to the topic of experiential involvement and user group organizations, with both issues fundamentally rooted in the concept of *essentialism* [14]. Broadly defined as a common trait or essence that unifies a group or collection

of things, essentialism becomes problematic in the context of women’s standpoint because it makes the ontological error of suggesting that women are a coherent category of persons. Critiques of essentialism emerged in second wave feminism from women of colour and women in poverty who charged that so called “women’s interests” had been dominated by a white, middle class understanding. This pivotal controversy spawned a pluralism of standpoints in third wave feminism and raised vexing challenges to feminist meta-theory [15]. Furthermore, the very notion that women were ontologically “other” presented a double-edged sword as being “other” was simultaneously the basis of their epistemic privilege as well as their subordination. The critique of essentialism helps us to understand why user groups or experiential persons often may have trouble identifying and maintaining the parameters of solidarity, a problem which is endemic to identity politics. As illicit drug use spans race, economic, gender and other aspects of material and social stratification, one can imagine that maintaining solidarity on the basis of present or former drug use can be problematic in a number of ways. Second, essentialism reveals a fundamental problem with reifying denigrated identities as a basis of epistemic privilege as it perpetuates the symbolic foundations upon which discrimination exists in the first place. In practice, the issue is that user groups and experiential persons may find deep fissures in experience and opinion on collective organizing, and second, elevating stigmatized aspects of identity to the fore of discussion, making them a “master status” of experience, can be a painful or otherwise undesirable experience for some individuals, even though this practice may, at the same time, be crucial to rewriting derogatory social understandings. In other words, being identified as a “user” may be perceived as highly reductionist and stigmatizing in its own way, even if the basis for doing so is well intentioned and critically strategic.

An additional body of social theoretical work supporting the knowledge claims of experiential persons has emerged from the social constructionist paradigm and is worth mentioning here because of its strong influence in the illicit substance and addictions academic literature. Social constructionism is a sociological theory of knowledge developed by Durkheim at the turn of the century, which was popularized in contemporary social theory by Schmaus [3] and Berger and Luckman [4]. The basic premise of social constructionism is that all knowledge, including the most mundane ideas, are produced in specific historical and cultural contexts and reconstituted in social interaction. Social constructionism therefore involves looking into the ways that social phenomena are perceived and reified in institutional practices and traditions of knowing and acting among actual actors and groups of actors. This theoretical framework has been highly influential among scholars studying the sociology of addictions and illicit substance use because it enables an alternative examination of the dominant discourses that have surrounded drug use historically, whilst simultaneously directing attention to the live material and symbolic consequences of these dominant - and in the case of illicit drug use - highly negative, constructions. Howard Becker, in his treatise on becoming a marijuana user, produced one of the classic examples of a social-constructionist-oriented account of drug use among a particular sub-culture of persons [17]. Many scholars have since developed this approach using an ethnographic method in an effort to cut through dominant tropes of illicit drugs - often emerging from non-experiential groups and institutions of social control - to understand drug use in various contexts and among various sub-groups of users. This body of work has been instrumental in revealing substance use as a widespread phenomenon across history, cultures, gender and economic positions with varying meanings and outcomes which are largely determined, not by the properties of substances, but rather by the structural and

symbolic context of use [10,18-20]. What is especially relevant about the social constructionist framework is not that proponents necessarily advocate the epistemic privilege of user groups per se, but rather that it directs our attention to knowledge as both situational, contextual and dynamic, and it reveals the manifold and coordinated layers of discursive and material social control that surround illicit drugs and the concept of addiction.

In sum, the theoretical tenets outlined above support the notion of experiential persons as having access to unique and often privileged knowledge emerging from particularities of their live day to day experiences and their positions vis-à-vis other social groups, particularly the dominant classes. In the case of oppressed populations, it is oppression that provides a unique vantage point from which to perceive and reformulate the injustices contained within dominant economic, political, and social orders. Experiential persons are therefore not only sources of privileged knowledge, but also key agents in social change. Further, social constructionist ideas remind us that all knowledge is situational, contextual and reconstituted in interaction. Thus, interaction between social groups - for example, between user and non-user groups - is bound to lead to the rewriting of dominant knowledge(s), if only gradually. All of these theoretical ideas bode well for those advocating for experiential participation. However, the concepts of hegemony, false consciousness, and essentialism foretell enduring problems and pitfalls that must be critically and strategically considered in the context of experiential politics. This is especially true in the context of politics emerging from groups of persons where both material and symbolic features of marginalization are often present, as is the case with many illicit drug consumers and the user groups that represent them.

We now turn to three contemporary models of experiential participation used in academic, community development, and government program and policy sectors. These models highlight the varying approaches that emerge from the theoretical propositions discussed above, with some being more closely rooted in specific emancipatory theoretical positions than others.

Contemporary Models of Experiential Participation

The following section outlines three contemporary models of experiential participation: Community-academic collaboration (including the use of Photovoice as a unique methodological approach), transformative community practice, and liberation theology. Similarities and differences between each of these models are discussed, including the roles, responsibilities and distribution of power each envision between experiential (insider) and non-experiential participants (outsider). It is noteworthy that experiential involvement is often carried out in the absence of a particular model as it has generally become accepted by policy makers, service practitioners, community activists, and academics alike as a pragmatic way of improving the reach and "on-the-ground" effectiveness of social policy and programming, or in the case of research, the uptake of research findings by identified stakeholders. This does not mean, however, that experiential involvement or the development of user groups is a straightforward process. As will be elaborated below, many have experienced unanticipated stumbling blocks in experiential organizing, including problems merging the ideas and ethos of different subcultures as well as structurally embedded practices, which characterize different sectors of knowledge production.

Academic-Community Partnerships

Much of the existing literature regarding the experiential voice

focuses on academic-community partnerships, and is largely written by academics [21]. Within the field of public health, for example, a number of studies and books have shown the link between empowerment, equity and health, and suggest that academic-community partnerships are an excellent way of advancing healthcare initiatives, particularly in marginalized communities [22].

Lewis and Maticka-Tyndale summarize the range of academic-community research partnerships in their typology of *classic*, *collaborative* and *experiential* research models [23]. The classic research model is described as a model in which the academic partner maintains control and primary influence over the research questions, research instrument, data collection and data analysis. Researchers may involve persons from the target experiential population in a consultative role; however, the project is primarily driven by the interest of the researcher [23]. The benefit of this model may be that it requires little of the negotiation and compromise that often leads to a protracted research process. The major drawback of this model is that it may be perceived as minimally inclusive of the views of experiential persons, and may therefore be regarded with skepticism or disdain by the target population, some of whom are likely to feel that their experiences are being exploited in order to further the portfolio of the researcher.

The collaborative research model involves a more equitable partnership between researchers and members of the target population and varies in terms of the roles assigned to the experiential and non-experiential partners. One of the central tenets of this model is that the researchers and experiential persons share some common research interests that are enhanced by the partnership model. The strengths of the collaborative model lie in the benefits of a team approach to research - the research process is informed by multiple perspectives, relationships of trust are (hopefully) developed that may be drawn upon in future research projects, access to the target population may be strengthened, and resultant findings are useable and relevant to a number of audiences. The main drawbacks with this approach are the time consuming nature of collaboration, negotiation and renegotiation among the various stakeholders in the research process and the potential that the research will in fact be undermined if differences in opinion and practice between the various contributors become insurmountable. Further, given the concepts of hegemony outlined above, serious questions are to be raised about the degree to which academics and non-academics equally contribute to a research process that is governed by the traditional parameters of academic knowledge production.

The third model outlined by Lewis and Maticka-Tyndale is called the experiential individuals/group as research [23]. This model is driven by people from the target population who initiates and carries out the research with the consultative assistance of academic researchers, when needed. The objectives and process of the research remain with the experiential researchers in much the same way the purpose and objectives are the primary domain of the academic in the classic model. The primary advantage of this model is that it is potentially more responsive to the research needs of the experiential group and their constituency. The downside from an academic perspective is that the results may not conform to the standards of rigor associated with specific disciplines. In addition, some marginalized groups are not in a position to mobilize resources to initiate or engage in research projects [24].

In practice, the above models are not mutually exclusive and might be better depicted as a continuum with elements combined in a single experiential-academic partnership. A further theoretical weakness in these models is they are not often grounded in a particular

epistemological or social change perspective; they often carry implicit assumptions about the views and opinions of academic researchers. Experiential groups and community members are often conceived of as standing in opposition to one another, when in fact, the perspectives of insiders (experiential groups) and outsiders (academics and some community stakeholders) are themselves quite diverse and may in fact cross-cut conceptions of difference and sameness carried by terms such as “academic,” “experiential” and “policy” partners. Making a similar critique of claims to epistemic privilege based on “insider” and “outsider” status, Merton argued that a combination of views arising from multiple positions in relation to the research topic results in the most rigorous knowledge claims [25].

One model of community-academic research contains a more explicit agenda of social change: Community-Based Participatory Research (CBPR). For example, in *Using Community-Based Participatory Research to Address Health Disparities*, Wallerstein and Duran describe a research model more closely tied to the theoretical tenets of consciousness raising and critical pedagogy discussed earlier: More than a set of research methods, CBPR is an orientation to research that focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts [26].

Wallerstein and Duran’s article deals with specific challenges that face those undertaking CBPR projects, such as the operation of power and privilege, issues of consent, oppression based on socially-constructed categories, and the relationship between research and social change. One example of CBPR methodology is Photovoice, which has three main goals: (a) to record and reflect personal and community strengths and concerns, (b) to promote critical dialogue and knowledge through discussion of photographs, and (c) to reach policymakers. It incorporates participant photography and photo-elicited interviews and as originally founded by Wang and Burris [27], Photovoice is based on three key theoretical frameworks. First, Paulo Freire’s approach to critical education in which every person is understood as capable of perceiving and dealing critically with the world if given the right tools [13]. Freire proposed that the visual image is a particularly powerful tool for critical engagement [13]. The second is feminist theory in which power accrues to “those who have voice, set language, make history and participate in decisions” [28]. Photovoice empowers by bringing “seldom-heard ideas, images, conversations, and voices into the public forum [28]. And finally, Photovoice has been informed by a community-based approach to photography as a way for ordinary people to use cameras for social change [28].

With roots in feminist theory, Photovoice values the experiences of women by: enabling their own photographic representation of their lives; using their photos to guide the interview and group discussions; and, engaging women in the analysis and interpretation of the images [29]. Photovoice provides an alternate to positivist ways of knowing by engaging women in photographing representations of their lived realities that bring to life the depth and breadth of their lives and burdens [29]. Wang suggests using Photovoice to address health concerns that have been overlooked, under-conceptualized or ignored yet may be central to women’s experience, which may include investigating the relationship between multiple social identities [29]. Using participant photographs to guide group discussions and individual interviews is a key method for disrupting the usual power dynamic between researcher and interviewee. Participant analysis of images by identifying meaning and themes is critical to the Photovoice method. Although in some circumstances, researchers engage in some visual analysis of images

[29], in order to maintain an empowering and participatory approach to the research, it is important that the participants undertake the principle engagement of images [29]. Photovoice is a very useful participatory method for women to document, critically analyze and improve the contexts that affect their health [29].

Photovoice was used by one of the authors in a research project that explored northern women’s lived experiences of substance use and mental health (www.envisioningchange.ca). Although not a CBPR project, Photovoice was used in this research to address some of the problems identified in classic research models. The use of participant photography in this study was primarily to: (a) deepen the level of self-reflection and engagement of participants with the research questions, (b) balance the inherent power imbalance between researcher and participant by allowing participant photographs to guide the interviews, and (c) enable women to share their lived realities and experiences through images and narrative. Using photography to engage participants in self-reflection about their personal and community concerns brings depth to their engagement in the research process and enriches the data and their overall experience [30]. Giving voice to seldom heard and marginalized members of society is one of the strong capabilities of Photovoice as a method.

As a final note, community-academic research models, while varying tremendously in terms of decision-making structures, often display traditional academic emphasis on textual documentation such as reports, articles and evaluations as the products of knowledge creation. The Photovoice method, such as the research outlined above, challenges the status quo, focusing on the photographic images and text created by those traditionally excluded in the production of research. Models emerging from the community, such as applied disciplines of social work and the practice of community organizing, often put greater emphasis on outcomes related to the process and to social change associated with collaborations between experiential and non-experiential groups. One such model, discussed next, is Transformative Community Practice (TCP).

Transformative Community Practice: The Canadian National Coalition of Experiential Women

Transformative Community Practice (TCP), as developed by Rabinovitch Jannit, includes the experiential community in the design, development and implementation of outcomes. TCP requires that the community in question play a decision-making role at every stage by breaking down barriers and building alliances. It offers an approach to community practice that engages the experiential community and thus has a transformational effect on all those involved-the participants, the change agents and the larger community [31].

TCP is open to participation from various groups including those with personal experience, those with professional training, academics and members of the larger community. It is a form of community practice that requires a degree of collaboration and partnership that may feel risky to those who are used to making decisions themselves [31]. To engage in a process of transformation requires letting go of expectations and allowing the process to dictate the outcome. Within the TCP model, four key guiding practices are identified [31]. First, TCP seeks to re-define notions of expertise to the experiential community thus ensuring they play a decision-making role in the design, development and implementation of all solutions intended to address their needs. Second, TCP requires the allocation of sufficient time and resources for the process of community practice so that it is possible to incorporate community members in a meaningful way.

Third, TCP identifies the change agent as a crucial non-experiential individual, outlining a role that includes acting as the “facilitator” or “broker” between the experiential community and the non-experiential community. Fourth, TCP recommends the development of a new understanding and process for defining measures of success. With regards to the role of experiential persons, TCP views them as the key to social change, suggesting that they take the lead to address their own concerns using their experience to define problems and set goals. TCP further suggests that experiential persons identify the activities that allow them to work toward individual and communal objectives as well as the outcomes that are to be associated with those activities. Finally, TCP suggests that experiential persons develop the ability to speak for themselves and be heard “on their turf and on their terms”. Social change that works from the centre out, engaging those most affected, leads to change that is more relevant, more likely to make a difference in people’s lives, and more likely to be sustained [31]. Professional policy and program planners and social change agents can make the greatest difference when they learn to plan from the experiential community outward rather than from the funding agency inward. Multiple, small, local solutions co-created by those most affected are more likely to be cost effective, relevant to participants, and to take root and spread rather than large top-down, bureaucratic programs.

Across Canada there are a number of local, regional, and national organizations to support sex workers and advocate for their rights. One example of experiential alliance is the Canadian National Coalition of Experiential Women (CNCEW). Part of the mandate of CNCEW is to identify opportunities to meet the needs of sex workers, and to have sex workers identify these needs and propose ways of addressing them. Through previous consultation with sex workers, CNCEW identified the requirement for support for experiential women who are seeking treatment for addiction to alcohol and other drugs. With funding from Status of Women Canada, CNCEW developed a substance use treatment model dedicated to meeting the unique needs of sex workers. It was piloted in the summer of 2007 at the well-established Crossroads Treatment Centre in Kelowna, British Columbia, Canada and at the Prostitutes Empowerment Education Resource Society (PEERS) Elements Program in Victoria, British Columbia, Canada. It was entitled *Sex Workers Addressing Treatment*, abbreviated to SWAT.

The SWAT program was guided by peer-education and empowerment principles, emphasizing that, experiential expertise is recognized as the starting point of the endeavor [32]. In other words, sex workers themselves developed, tested, critiqued, and revised the curriculum for the SWAT workshops. In this respect, the SWAT program was a peer-based model: a sex worker-specific substance use treatment program for sex workers developed by sex workers. An evaluation of the program revealed three important and positive themes: participants did not feel isolated or shamed (responses common to other programs); participants experienced a sense of hope; and participants learned how to give and to accept support.

Liberation Theology

A third model of experiential involvement, Liberation Theology, emerging from faith based community development, was used in the development of perhaps the most prominent group of drug users, the Vancouver Area Network of Drug Users (VANDU). Liberation Theology is a movement within the Roman Catholic faith that focuses on the political emancipation of the poor from the oppression of social and governmental power structures. The movement was developed in Latin America and combines Christianity and Marxism as means of promoting the legitimate participation of the poor in religion and

politics. Four ideals have been central to this movement, including the preferential option for the poor (the church aligning itself with poor people as they demand justice), institutional violence (Liberationists see a hidden violence in social arrangements that create hunger and poverty), structural sin (arguing that there is a social dimension that is more than the sum of individual acts), and orthopraxis (‘correct action,’ leading to human liberation) [33]. Placing a premium on social analysis, Liberation Theology believes that one must first understand the social mechanisms that produce it. To do this, many liberation theologians were drawn to Marxism.

In response to the HIV epidemic among injecting drug users in the Downtown Eastside of Vancouver and drawing on the tenets of Liberation Theology outlined above, the Vancouver Area Network of Drug Users (VANDU) was formed as a nonprofit organization with the assistance of Ann Livingston and Bud Osborn and currently claims a membership of over 1500 individuals. Full membership in the organization is open to anyone who has used illicit drugs, with supporting membership open to those who have not. VANDU undertakes activism, advocacy, and public education, and care and support programs, based on the philosophy of involving and empowering drug users.

In keeping with their goals and beliefs, VANDU is committed to increasing the capacity of people who use drugs to live healthy productive lives. They do this by affirming and strengthening people who use drugs to reduce harm to themselves and their communities. They organize in their communities to save lives by promoting local, regional and national harm reduction education, interventions and peer support [34]. VANDU also believes in every person’s right to health and well-being, recognizing that the realities of poverty, racism, social isolation, past trauma, mental illness and other inequities increase people’s vulnerability to addiction and reduce their capacity for effectively reducing drug related harm.

The March 2006 edition of the *International Journal of Drug Policy* was one of the first journals to feature articles by community members and their allies involved in user-run organizations in British Columbia. Douglas et al. published a community-based case study of VANDU, following government inaction in dealing with a number of drug overdose deaths and health epidemics ravaging the Downtown Eastside [35]. Douglas is very specific about the community consultation that was undertaken before VANDU was set up, the kind of work the organization does, as well as how it is structured and operates [35]. The author concludes that the formation of drug user organizations is highly beneficial for community health and should be encouraged, as well as suggesting that the work of such organizations should be incorporated into public health policy, education, planning and programs. In their representation of VANDU, Douglas provides a model that can be used by others in designing and implementing an organization run by drug users.

Bud Osborn and Will Small respond to the Douglas article ‘*Speaking Truth to Power: The Role of Drug Users in Influencing Municipal Drug Policy*’ [36]. This response focuses on the impact VANDU has had, testifying to its success in empowering drug users, both in terms of getting the voices of drug users to be taken seriously in the political arena, as well as getting community members involved in helping themselves and their peers. The authors also touch on how the organization and its allies work together with the group’s supporting members deferring to those with full membership status [36]. Unlike the Douglas article, Osborn and Smith do not go into much detail about the organization’s structure or activities, instead choosing to convey to readers a sense of the positive influence VANDU has had, and continues to have, in the Downtown Eastside community.

Examples of successful user-run organizations are not limited to Vancouver. In Australia, user-run organizations lead by those who use drugs are highly successful. In an article covering the history and effects of such organizations, Nick Crofts shows the extent of positive influence these groups have exerted in response to health issues like HIV/AIDS, as well as how they approach the challenge of doing their work when government officials designate the “epidemic (as being) over” [37].

While the articles on user-run organizations are very useful to those interested in learning about the work they do, perhaps the body of literature that best captures the spirit of a marginalized group proclaiming its right to assert its own voice in healthcare is found in *Nothing About Us Without Us: A Manifesto by People Who Use Drugs* [38]. Published by the Canadian HIV/AIDS Legal Network, the document is clear in its view that people in a particular community need to be involved, if not lead, projects related to their own health: We have the right to become involved in activities that affect our health and well-being. We have the right to be able to make informed decisions about our health, including what we do and do not put into our bodies. We have unique expertise and experiences and have a vital role to play in defining the health, social, legal and research policies that affect us [38].

The same group published a report accompanying the manifesto which clearly lays out why it is important to individuals who use drugs to be involved in HIV/AIDS and Hepatitis C prevention work, as well as suggesting steps to accomplish their increased meaningful involvement which will be outlined later [38]. The need for those traditionally marginalized to become involved in all areas of research, planning and delivery related to their communities is highlighted as being of critical importance. The resources, however, tend to be divided between “top-down” participatory action research initiated by academics and existing organizations, and “bottom-up” organizing done by experiential groups without significant help from “outsiders.” What has not been covered so far and deserves special consideration are the themes of success and challenge emerging from the literature on experiential participation models and experiential groups.

The Experiential Movement: Benefits and Pitfalls

Several benefits of experiential participation have been identified in the literature and have been alluded to in the previous section. First, improved knowledge that takes into account the lived experience of individuals is generated, as noted in the document produced by the HIV/AIDS Legal Network [38]. Second, policy and programming initiatives are more effective when experiential knowledge is effectively incorporated. Third, consciousness raising and social capital building among marginalized groups enable these individuals to take a stand for their rights and express what they need, as was the case with the CNCEW. Years of activism and political lobbying resulted in the “forward thinking” of health officials, government, and politicians, which enabled the creation of the SWAT model. Fourth, experiential participation allows for the use of a social constructionist framework to disrupt dominant knowledge with counter interpretation emerging from marginalized groups.

VANDU identified a number of benefits in their report *nothing about us without us* [38]. Fulfilling the commitment to greater involvement of people living with HIV, those who use drugs represent a significant proportion of the people, in Canada and many other countries, which contract HIV. This means that governments and organizations can no longer claim that they involve people with HIV adequately in their work on HIV/AIDS without meaningfully involving one of the most

marginalized groups of people living with, or at great risk for, HIV. There are public health imperatives for involving people who use illicit substances. People who use illicit substances themselves are often best able to identify what works in a community that others know little about and must be involved if we want to create effective responses to the HIV epidemic [38]. Research both within Canada and internationally provides evidence of the benefits of greater involvement of people who use illicit substances. The limitations of the traditional provider-client model, in which service providers strive to meet the needs of people who use illicit substances, are increasingly recognized [38]. People who use illicit substances have demonstrated they can organize themselves and make valuable contributions to their community, including: expanding the reach and effectiveness of HIV prevention and harm reduction services by making contact with those at greatest risk; providing much needed care and support; and advocating for their rights and the recognition of their dignity, as outlined above. There are ethical and human rights imperatives for the greater involvement of people who use illicit substances. As an ethical principle, all people should have the right to be involved in decisions affecting their lives [39].

The literature has also identified several pitfalls associated with experiential participation, many of which are embedded in the theoretical concepts of hegemony and essentialism introduced earlier, and others which are associated with the co-occurrence of both material and symbolic marginalization, typically found among user groups whose experiential backgrounds include multiple marginalization (such as sex work, homelessness, low literacy, and/or mental health issues). The first pitfall concerns tenuous alliances and solidarity among some experiential groups. A second pitfall involves the concept of hegemony. For example, VANDU was highly instrumental in advocating for the construction of a safe injection facility, even operating a peer run safe injection site in the waiting interim period as a means of protest. Despite their pivotal role in bringing this harm reduction innovation to their community, they were ultimately excluded from the process when the federal government approved the development of Insite Supervised Injection Site [39]. Because they had no say in the actual design of the facility, the end result was a safe injection site many have described as less than user friendly [39]. Insite would have been designed in a different way if VANDU had the opportunity to be involved in its development. This experience speaks to the “glass ceiling” that experiential organizations face when it comes to policy and institutions of social control/surveillance. A third pitfall concerns cooptation and tokenism, whereby ideas of experiential groups are subsumed and reframed in unexpected ways by the dominant group - ways which violate the original intention and are otherwise unable to exercise influence in the context of coordinated regimes of knowledge making (hegemony). A final pitfall concerns how essentialism in identity politics leads to reinforcement and/or elevation of negative identities to a “master status”, as discussed earlier. Many experiential individuals will not be comfortable being identified in a public way as a drug user, and therefore these groups do not always represent their full constituency. Further to this, the general insider/outsider rhetoric leads to reification of non-existent solidarities and alliances while at the same time can cause groups to overlook their potential alliances and partnerships. Certain individuals without experience may have little interest in a cause and/or be opposed to it. Similarly, heterogeneity is important to consider among the opinions within user groups. Some may support abolition and others may support harm reduction orientations, with both viewpoints emerging directly from experience. Alliances outside the experiential community and across sectors may be especially important in the context of socio-economically marginalized groups;

however, at the same time, individuals must always be cautious of cooptation and hegemony, as previously discussed.

Recommendations

The literature documenting lessons learned in experiential group organizations suggests a number of practices that facilitate success. First, mentorship and support relationships should be established between individuals with more experience and those learning about the organization [31]. In the case of drug user organizations, some thought needs to be given to the level of interaction between those who are actively consuming illicit substances and those who have recently discontinued their use [40]. Scheduling opportunities for individuals to specifically communicate how they are feeling about their involvement and to provide feedback on the process can help to identify potential problems before they escalate and can facilitate newcomers to feel supported. Guiding principles for communication established collectively can also help facilitate communication regarding controversial issues that hold deep importance for experiential persons. Given the context of experiential participation among economically marginalized groups, many also advocate for adequate resources to be made available such as honoraria for participation, transportation costs, meals, childcare, and other basic necessities [31].

Organizations such as VANDU and the CNCEW also advocate for rotating decision-making structures to ensure that participants have the opportunity to develop skills related to the various roles and to discourage the prospect of an elite few unduly representing the entire membership. Alliances with key persons outside the experiential group and the maintenance of alternative position stance vis-à-vis dominant institutions and discourses are extremely important to ensure that mainstream society has access to this knowledge through public education initiatives which enhance the marginalized group's visibility within the community.

Conclusion

This paper has outlined the theoretical foundations for the epistemic privilege claimed by experiential groups and the role of marginalized populations in emancipatory social change. Inclusion of the experiential voice is increasing within government, academic and community service and advocacy sectors, with various models emerging, each based in slightly divergent institutional understandings of knowledge and social change and associated with different relationships between "insiders" (experiential persons) and "outsiders" (traditional experts and other members of the non-experiential community).

The existence of user groups such as VANDU and the CNCEW representing the interests of marginalized individuals has had a profound impact on the adoption of harm reduction principles internationally and has proven that the experiential voice is a necessary challenge to dominant tropes and discourses surrounding illicit substance use, which depict illicit substance users as conduits of infection, criminals and/or as lacking any will or moral agency. While the health concerns surrounding the intersection of some aspects of illicit drug use and poverty can be severe, marginalized drug users have ready and immediate access to lived experience and can be powerful spokespersons for their peers, reminding experts of the many details overlooked in solutions emerging from outside the experiential community. However, the concepts of hegemony and essentialism, the lack of resources made available to discriminated groups, and the tricky business of forming alliances with non-experiential groups must be strategically considered as they pose enduring barriers to groups formed around discriminated identities who seek to disrupt established, coordinated systems of thought and

social control. Many best practices have emerged in the community based and academic literature regarding experiential involvement. These practices include setting aside resources to help overcome social and material barriers to participation, framing issues in a manner so as to maximize applicability to heterogeneous interest groups, developing decision making structures which encourage widespread involvement as opposed to elite management, and developing key relationships with supportive persons outside experiential groups whose focus is enabling the philosophies and contributions of experiential persons. Also, as the concepts of hegemony and cooptation allude to, experiential groups must be strategic about the degree to which they seek to mainstream themselves versus the degree to which they maintain an alternative voice placing pressure on, and exposing the contradictions of, institutionalized, "expert" discussions: You always need loud vociferous folks out there on the edge so the centre moves...and you can't ignore those guys (VANDU). They're vocal, they're very passionate and they are trying to hang on to the agenda until something significant occurs [35].

As more and more experiential groups emerge in Canada representing local, regional and national interests, further research is required and, more particularly historical research, which seeks to understand the impact of the experiential movement in Canada over the last 25 years. Such research would likely reveal distinct patterns in terms of where these groups have had the most and the least impact and would therefore be instructive as we think about moving the experiential agenda forward in the coming years.

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