

Protecting Peer Support Values and Ethics Through Community-Engaged Bioethics

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Advocates, Activists, Architects of Moral Space?

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Article abstract

There has been a long history of cross-pollination between peer support (PS) in the United States and Canada, but collaboration has declined over the past two decades as PS has become increasingly professionalized. With government recognition and funding, PS has moved from informal friendships in the community among those with similar lived experiences towards paid PS employment in clinical services. In this commentary we argue that PS in Canada and the US should return to working together. We share ethical challenges related to the professionalization — and associated co-optation and drift — of PS, where PS deviates from its unique grounding in authentic human connection, social movement organizing, and core values of self-determination, shared power, hope, and mutuality. The resulting loss of the transformative power of PS is particularly potent in our current moment when it has so much to offer. We describe how our team of community-engaged bioethicists from Canada and the US and leaders of the PS discipline in Canada are collaborating to elaborate, legitimize, and protect the unique values and ethics of this expanding and evolving modality of care.

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TÉMOIGNAGE / PERSPECTIVE

Protecting Peer Support Values and Ethics Through Community-Engaged Bioethics

Lee de Bie^{a,b,c}, Julia Knopes^d, Allison Dunning^e, Allyson Theodorou^f, Brookelyn Fortier^e

Résumé

Il existe une longue histoire d'échanges fructueux entre le soutien par les pairs (SP) aux États-Unis et au Canada, mais la collaboration a diminué au cours des deux dernières décennies, le SP s'étant de plus en plus professionnalisé. Grâce à la reconnaissance et au financement du gouvernement, le SP est passé d'amitiés informelles au sein de la communauté entre personnes ayant vécu des expériences similaires à un emploi rémunéré dans les services cliniques. Dans ce commentaire, nous soutenons que le SP au Canada et aux États-Unis devrait recommencer à travailler ensemble. Nous partageons les défis éthiques liés à la professionnalisation — et à la cooptation et à la dérive qui y sont associées — du SP, qui s'éloigne de ses fondements uniques que sont les relations humaines authentiques, l'organisation de mouvements sociaux et les valeurs fondamentales d'autodétermination, de partage du pouvoir, d'espoir et de mutualité. La perte de pouvoir transformateur du SP qui en résulte est particulièrement importante à l'heure actuelle, alors qu'il a tant à offrir. Nous décrivons comment notre équipe de bioéthiciens engagés dans la communauté au Canada et aux États-Unis et les leaders de la discipline SP au Canada collaborent pour élaborer, légitimer et protéger les valeurs et l'éthique uniques de cette modalité de soins en pleine expansion et en constante évolution.

Mots-clés

bioéthique communautaire, cooptation, dérive du soutien par les pairs, professionnalisation, mouvement des survivants de la psychiatrie

Abstract

There has been a long history of cross-pollination between peer support (PS) in the United States and Canada, but collaboration has declined over the past two decades as PS has become increasingly professionalized. With government recognition and funding, PS has moved from informal friendships in the community among those with similar lived experiences towards paid PS employment in clinical services. In this commentary we argue that PS in Canada and the US should return to working together. We share ethical challenges related to the professionalization — and associated co-optation and drift — of PS, where PS deviates from its unique grounding in authentic human connection, social movement organizing, and core values of self-determination, shared power, hope, and mutuality. The resulting loss of the transformative power of PS is particularly potent in our current moment when it has so much to offer. We describe how our team of community-engaged bioethicists from Canada and the US and leaders of the PS discipline in Canada are collaborating to elaborate, legitimize, and protect the unique values and ethics of this expanding and evolving modality of care.

Keywords

community-engaged bioethics, co-optation, peer support drift, professionalization, psychiatric survivor movement

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INTRODUCTION

Peer support (PS) is, in its most expansive sense, “a naturally occurring, mutually beneficial support process, where people who share a common experience meet as equals, sharing skills, strengths and hope; learning from each other how to cope, thrive and flourish.” (1) Formal PS “begins when persons with lived experience who have received specialized training, assume unique, designated roles...to support an individual's expressed wishes.” (1) Although formal PS is a growing approach to relational support that can improve mental health outcomes, address health disparities, and reduce healthcare costs (2), it has been under-supported by bioethicists.

There has been a long history of cross-pollination between PS in the United States and Canada, but collaboration has declined over the past two decades as PS has become increasingly professionalized. With government recognition and funding, PS has moved from informal friendships in the community towards paid PS employment in clinical services (3). In this commentary, we argue that we should return to working together through shared ethical challenges related to the professionalization — and associated co-optation and drift — of PS. We describe how community-engaged bioethicists can support the PS discipline in elaborating, legitimizing, and protecting the unique values and ethics of this expanding and evolving modality of care.

HISTORICAL INTERCONNECTEDNESS OF PEER SUPPORT IN CANADA AND THE US

PS in Canada and the US has a long and shared history. One tradition of PS commonly practiced today in health systems in Canada was inspired by the advocacy, community organizing, and self-help initiatives of the 1960s-1970s psychiatric

consumer/survivor/ex-patient (C/S/X) movement in the US, which was informed by — and interconnected with — other liberation movements of the era (4).¹ For example, the critiques of scholars writing from the US, such as Goffman (7-8) and dissident mental health professionals like Chesler (9) and Szasz (10-12), fueled the movement in both countries, at a time when there were few such leaders in Canada (13-15). These authors' critical analyses of the psychiatric system helped PS emerge as a less harmful alternative.

The 1980-1990 production of *Phoenix Rising*, a Toronto-based national psychiatric survivor newsletter, was inspired by the American *Madness Network News* (15), and the online publication *Mad in Canada* arose as an affiliate website of the widely-read *Mad in America*, founded in 2012. These publications played a significant role in spreading PS knowledge and practice. The 1990s development of "recovery philosophy" in the US, which emphasizes how individuals can live purposeful, hopeful, and meaningful lives even in the midst of mental health challenges (16-17), became a key principle of PS in Canada in the early 2000s (18). *Making the Case for Peer Support*, the foundational document promoting the expansion of PS in Canada, heavily references research evidence and best practices from the US (3).

This influence is bidirectional. For example, Judi Chamberlin, a key leader in the American psychiatric survivor movement, dedicates a full chapter of her 1978 seminal book to describing her visit to the Mental Patients Association in Vancouver (19). The expansion of Mad Pride in the US and internationally as a community-building initiative and alternative to biomedical paradigms was informed by early 1990s Psychiatric Survivor Pride Day activities in Toronto (20-21). The Canadian development of Mad Studies in the 2000s, an academic discipline emerging from the C/S/X social movement, has also spread to inform PS in the US and beyond (22-23).

This flow of ideas between the US and Canada has informed the design of PS programs, and the consolidation of PS values and ethics (24). Without US "evidence" of peer support's legitimacy and effectiveness, our uptake of this approach in Canada would have been significantly delayed.

SHARED PRESENT-DAY CONCERNS ABOUT PROFESSIONALIZATION AND PEER SUPPORT DRIFT

Over the past two decades, PS has become increasingly professionalized. There is a growing expectation that peer supporters complete training and certification before they go on to work within clinical environments. While both countries have tracked a similar trend, the speed and scale of professionalization in the US have greatly surpassed that in Canada. For example, in 1993, New York was the first US state to establish a formal "peer specialist" role title, conveying recognition of unique expertise (25). In 1999, Georgia became the first state to allow government-funded Medicaid billing for peer support services, which was expanded nation-wide in 2007 (25-28). As of 2014, 38 US states had peer specialist certification programs that required completion of a state-approved training course and/or multiple-choice exam (25,29). In contrast, Canada has a national, voluntary, PS certification program that is peer-run with no government influence.

While training and certification requirements can ensure that peer supporters have the necessary skills to journey with people in their recovery, PS practitioners and scholars have critiqued these mechanisms in the US as a loss of self-governance and control over PS education that poses a risk of great harm to the integrity of the practice. For instance, Penney and Prescott raise alarm that some state-based programs do not include training on the core values and history of grassroots PS (25). When clinical training (e.g., in diagnoses, therapies) is valued more than lived experience, or overrides or replaces experiential skills and knowledge, PS experiences epistemic injustice, drifts from its roots in authentic human connection and civil rights struggles, and fails to offer a distinct alternative to traditional health services (24,29). Activists in the C/S/X and PS movement have worried about this threat — most often called "co-optation" in US scholarship, and "peer (support) drift" in Canada — for many years, but we're seeing increased concern among US and Canadian practitioners, as well as those writing from the UK, Australia, Germany, and internationally (42-47).²

PS drift is an ethical problem caused by a deviation from the unique PS values of self-determination, shared power, hope, voluntariness, mutuality, and social justice (25,39,48). Dynamics pushing peer supporters to drift from their values are complex. As an example, many peer supporters in Canada hold precarious and isolated roles in workplace cultures that are often incongruent with PS values (e.g., hierarchical provider-client relationships; medical diagnoses that take away a person's power of self-definition; use of non-voluntary, paternalistic, and coercive practices of social control) and do not respect their lived experience. It is difficult to continue the emancipatory impulse of the C/S/X social movement and challenge the status quo when they lack power and support to do so (3,48).

Additionally, in a clinical environment where non-peer supervisors and colleagues misunderstand the unique role of PS, peer supporters are often directed to set more rigid, emotionally detached, "professional" boundaries akin to those of clinical professionals (38). These expectations prevent them from performing the core responsibility of the PS role, which is to draw

¹ While beyond the scope of this commentary, it is important to note that both Canadian and US psychiatric survivor and peer support movements have been influenced by international efforts, especially those in the United Kingdom and global efforts to protect human rights (5-6).

² For example, a search of the blog *Mad in America* returned 1010 hits for the keyword "co-optation" and only two for "peer drift". Other American texts also tend to adopt the term "co-optation," (19,25,26,30-37) while "peer (support) drift" is the more common term in Canada (38,39). Our best guess is that this phrase was popularized in the Canadian PS community by Theresa Claxton-Wali (40), a North Toronto-based PS leader, inspired by the work of US Veterans Affairs (41).

on and meaningfully disclose their lived experience to build mutual and trusting relationships with peers and facilitate the sharing of power and learning (42).

PS drift causes significant harm and loss to health systems, society, and peer supporters. Crucially, when values-based PS is practiced with integrity, it has a unique ability to bridge gaps in the healthcare system, address the unmet needs of marginalized groups, and reduce stigma and isolation through the rebuilding of relationships and community. When PS drifts from its special role and essential features and duplicates conventional health services, we are deprived of these health equity-enhancing possibilities, and peer supporters themselves can be harmed through moral injury, exploitation, and a waste of their capabilities (48-50).

This loss of the transformative power of PS is particularly potent in our current historical moment. PS emerged as a successful response to the 1960s-1970s upheaval of oppressive societal structures, authority, laws, traditions, and norms through the creation of radical self-help alternatives (4,27). PS can do so again now, preventing the pathologization and medicalization of human distress and supporting individuals and communities in weathering our current times (51,52), if its core values and outcomes are preserved.

THE DECLINE OF PS INTERCONNECTEDNESS IN THE WAKE OF PROFESSIONALIZATION

The increasing turn to the professionalization of PS over the past two decades has focused inward, locally, provincially, and nationally, and taken us away from cross-national collaboration. In the US, many PS initiatives are now tied to state-based certification and Medicaid funding. In Canada, PS became increasingly valued as a component of the publicly-funded Canadian health system when the Mental Health Commission of Canada was established and published the first national mental health strategy in 2012 (53).

While government funding has supported internal capacity building of PS initiatives in Canada, the PS discipline has not been afforded adequate resources to facilitate sustainable provincial or national PS conversations, much less international ones. Additionally, the majority of Canadian advocacy to address PS drift and protect PS values is necessarily directed locally — at government policy, funding models, health system restructuring, and community partnerships (48). This loss of Canadian-US collaboration arguably weakens our national and international PS movement.

To address co-optation, peer supporters are encouraged to connect to the psychiatric survivor movement and its values and struggle for human rights and self-determination (30). In Canada, we've started returning to stories about the "roots" of PS in the psychiatric survivor movement, histories often interwoven with activism from the US (48,54). We need to collectivize beyond state-based borders.

FUTURE DIRECTIONS: COMMUNITY-ENGAGED BIOETHICS TO ADVANCE PEER SUPPORT ETHICS

One recommendation for preventing and addressing PS drift that emerged through consultations with peer supporters across the province of Ontario is to further consolidate ethical guidelines specific to the PS role (48). We therefore came together as a team of two bioethicists with backgrounds in PS (one from Canada, and one from the US), the Executive Directors of the national Canadian and provincial Ontario PS associations, and several supporting peer supporters and academic colleagues, to explore how to best support PS ethics.

Funded by research planning and knowledge translation grants from the Canadian federal government, we are pursuing several activities. First, we have observed that the esoteric academic theory and concepts of "ethics" are rarely discussed in PS communities (or when they are, have been noted to be inaccessible) (55). Yet we wondered how an effective translation of academic ethics tools into PS language and practice might help the PS discipline address its serious concerns about co-optation and drift from PS values. We thus developed a 4-session Community of Practice on PS ethics that we have facilitated with three cohorts of peer supporters from across Canada, using several ethical reflection tools we have adapted for a PS audience.

Second, PS ethics have been cultivated orally within PS communities for decades but have not been well defined and documented in the ways that tend to garner broader recognition and respect (3). Accordingly, we are engaged in national consultation about potentially developing a PS Code of Ethics. We are deepening our understanding of the shared challenges we face as peer supporters across Canada and national borders, and areas of potential consensus and difference regarding PS ethics, as influenced by the diverse organizational contexts in which peer supporters practice, as well as individual variation in peer supporters' values and beliefs. We hope that this consensus-building project can help us collectivize across Canada, as well as help us communicate with PS associations internationally.

Third, our collaborative work aims to re-ignite the flow of ideas and collective momentum between the Canadian-US-international PS movements through development of the (currently very limited) international academic literature on PS ethics (56). Further scholarship on PS ethics can help describe and validate the skill and intentionality that peer supporters bring to their work, the values and social movement traditions that ground their approach, and how their ethical practices are

no less valid and robust than those of other health professions (56,57). Contributing to the evidence base for PS can help practitioners defend the legitimacy of their practices and resist PS drift. We are therefore working to strengthen relationships with interdisciplinary researchers, ethicists, and peer supporters to begin conceptualizing a future research project.

Bioethicists have a role to play in supporting the PS discipline (56). The risk for co-optation and drift of PS is highest in the conventional healthcare settings in which bioethicists predominantly work, but we are unaware of examples of bioethicists beyond our team who are collaborating with peer supporters to address these concerns.³ Furthermore, we must address the critique that bioethics is largely focused on the dramatic clinical ethics issues in in-patient healthcare settings and poorly engaged in organizational ethics and supporting our communities, including predominantly community-based peer supporters, with their everyday ethical questions and needs (60). PS values and ethics are a promising antidote to our current crisis. They deserve our full support.

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Conflicts of Interest

None to declare

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³ The limited bioethics literature on PS responds to a fundamentally different context of alleviating the moral distress of healthcare workers through PS (58-59).

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