A scoping review of ethical considerations when responding to the needs of people who use drugs during public health emergencies: Working paper (search inclusive of August 20th, 2020)

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This review is part of a larger knowledge synthesis strategy proposed by the team, responsible for the CIHR funded study "Converging epidemics and the health for people who use drugs: Using evidence to move decision making into action in the context of COVID-19"

Abstract:

Introduction: The novel coronavirus (COVID-19) pandemic has arisen in the context of a preexisting opioid overdose crisis, which has taken the lives of 14,700 Canadians. Health and human services are responding with emergency protocols but some of these have resulted in reduced service levels, including for harm reduction and addiction treatment services. Evidence synthesis is critically needed to support ethical research, practice, and policy decision-making specifically for people who use drugs (PWUD). We conducted a rapid dual-pronged scoping review about relevant ethical considerations (defined broadly) to inform the research, clinical, and public health response to support PWUD during the emergency created by the COVID-19 pandemic.

Methods: We conducted a two-pronged scoping review following PRISMA scoping review guidelines and our own experience (combined in a single review for rapid dissemination). We were interested in the intersection of ethics, PWUD, and COVID-19 and other related past public health emergencies (e.g., Severe Acute Respiratory Syndrome (SARS), Middle East Respiratory Syndrome (MERS), and Influenza A virus subtype H1N1).

Results: Overall, few academic and grey resources explicitly discussed ethical issues related to the needs of PWUD during COVID-19 and the other similar public health emergencies. Some emerging guidance points to stigma and access as key ethical issues and identifies considerations related to professional ethics.

Conclusion: Future research is needed and should be conducted in consultation with communities of PWUD and other research, clinical and public health stakeholders to develop explicit formal ethical guidance and decision-making tools.

Introduction: The novel coronavirus (COVID-19) pandemic has arisen in the context of a preexisting opioid overdose crisis, which has taken the lives of 14,700 Canadians.¹ This "dual public health emergency"² for people who use drugs (PWUD) is occurring within a complex context characterized by high levels of vulnerability arising from the criminalization of drugs; stigma, racism, colonization, interpersonal and gender-based violence; housing, income and food insecurity; and poor access to health and social services.³⁻⁸ These inequities are closely linked to the risk of HIV and other sexually-transmitted and blood-borne infections (STBBIs) and poor health outcomes compared to people who do not use criminalized drugs.⁹⁻¹⁴ The rapidly evolving COVID-19 pandemic is already disproportionately impacting PWUD (and especially socio-economically marginalized PWUD) leading many HIV and addictions specialists, community-based organizations, and communities of PWUD to call for immediate emergency responses.^{2,15-17} The Canadian Association of People who Use Drugs (CAPUD) and others are advocating for harm reduction services to be deemed essential lifesaving services and assisting organizations to modify their programs in response to increasing requests for physical distancing, and disruptions to social and community services and programming. Complex issues have been identified related to pandemic responses in terms of research ethics, clinical ethics, and public health ethics.¹⁸⁻²¹ However, these considerations are often defined and applied broadly. Evidence synthesis is critically needed to support ethical research, practice, and policy decision-making specifically for PWUD within this evolving pandemic. Activity: We conducted a rapid dual-pronged scoping review about relevant ethical considerations (defined broadly) to inform the research, clinical, and public health response to support PWUD during the emergency created by the COVID-19 pandemic. Our search was 'horizonal' and retrospective in that we asked two research questions:

- 1. What ethical issues have been identified in the emerging COVID-19 related academic and grey literature pertaining to people who use drugs?; and
- 2. What ethical issues have been identified in the established academic and grey literature about similar past outbreaks (e.g., SARS, H1N1) pertaining to people who use drugs?

Methods and search strategy: We conducted a two-pronged scoping review following established methods and our own experience (combined in a single review for rapid dissemination). ²²⁻²⁵ We were interested in the intersection of ethics, PWUD, and COVID-19 and other related past public health emergencies (e.g., Severe Acute Respiratory Syndrome (SARS), Middle East Respiratory Syndrome (MERS), and Influenza A virus subtype H1N1). The H1N1 pandemic of 2009, in particular, generated considerable discussions about ethics, ²⁶⁻²⁹ including for marginalized populations.³⁰ For our purposes, we were interested in ethics broadly, inclusive of normative ethics (e.g., theories and frameworks for how researchers, clinicians, and health systems *ought* to act) and descriptive ethics (e.g., investigations of attitudes and preferences). We included articles that were not solely focused on PWUD, but they had to have

a link between PWUD, ethics, and COVID-19 or another comparable public health emergency. While SARS and MERS remained outbreaks and did not progress to pandemic scale, they are also coronaviruses with similar disease profiles, and SARS was an early focus of ethical analysis.³¹ We did not search for HIV (which has an established evidence-base), hepatitis, and tuberculosis, and Ebola because of their transmission profile relative coronaviruses and influenza viruses), but they came up in our searches.

Question 1: Utilizing PRISMA scoping review guidelines³² KR searched several key health, social, psychology and interdisciplinary databases, namely CINAHL, Embase, Medline, PsycINFO, PubMed, Scopus, and Sociological Abstracts, using the following terms: ((COVID OR coronavirus OR "SARS-CoV-2") AND (Ethic*) AND ("people who use drugs" OR PWUD OR IDU OR inject* OR addict* OR "drug us*" OR cocaine OR stimulant OR cannabis OR alcohol OR opioid OR opiate OR methamphetamine OR psychedelics OR marijuana OR heroin OR crack OR "drug abus*" OR "drug misus*" OR "substance us*" OR "substance abus*" OR "substance misus*")). Searches were restricted to English-language only sources, and search terms could appear in any fields. The timeframe was restricted to sources published in 2019 or later. The searches were originally conducted on June 11th, 2020 and updated on August 19th, 2020. A concentrated search of the same databases was conducted on June 17th, 2020 and updated on August 19th using the terms: ((COVID OR coronavirus OR "SARS-CoV-2") AND ("people who use drugs" OR PWUD OR "people who inject drugs" OR PWID OR "substance user" or "drug user")) while adhering to the same restrictions above and also restricting the search terms to the Title/Abstract/Keyword fields. This allowed us to capture sources that dealt with issues of ethics but did not necessarily use this term. We also searched the Canadian Centre on Substance Use and Addiction (CCSA) databases for COVID and drug use related grey literature (e.g., municipal/health organization reports, guidelines, etc.) for any mention of ethical issues, and the Canadian Drug Policy Coalition and the International Network of People Who Use Drugs (INPUD). AG and KR collaborated on the search strategy and shared it with the wider team (CS, MG, NT, and MB) for comment.

Search results were managed using EndNote X9. A total of 392 sources were identified through the database search and an additional 20 sources were identified by searching the grey literature and the CCSA database and the Canadian Drug Policy Coalition and the International Network of People Who Use Drugs (INPUD) websites. Bramer et al. 's (2016) de-duplication method was utilized to remove duplicate results in EndNote X9.³³ After de-duplication 287 sources remained. All titles and abstracts were screened for eligibility according to the following criteria: a) sources looking at COVID-19; b) sources that investigate people who use drugs, deal with issues of substance use/addiction, and services provision (health care, harm reduction, mental health, etc.); c) sources that discuss issues of ethics (e.g., public health, clinical, research ethics; including terms such as rights, morality, duty of care, etc.) or use

ethical frameworks. KR screened all sources initially. AG subsequently reviewed any sources where there was uncertainty. KR and AG discussed these issues by phone until the uncertainty over sources were resolved. A total of six sources were included in this scoping review.

Question 2: We used PRISMA scoping review guidelines guidelines³² to search key databases (i.e., CINAHL, Embase, Medline, PsycINFO, PubMed, Scopus, and Sociological Abstracts) for articles and other sources that examined previous coronavirus and influenza pandemics and people who use drugs, and the ethical issues that arose. KR searched the above-mentioned databases using the following search terms: (("Severe Acute Respiratory Syndrome" OR SARS OR "Middle East Respiratory Syndrome" OR MERS OR "Influenza A" OR H1N1 OR coronavirus) AND (Ethic*) AND ("people who use drugs" OR PWUD OR IDU OR inject* OR addict* OR "drug us*" OR cocaine OR stimulant OR cannabis OR alcohol OR opioid OR opiate OR methamphetamine OR psychedelics OR marijuana OR heroin OR crack OR "drug abus*" OR "drug misus*" OR "substance us*" OR "substance abus*" OR "substance misus*")). Searches were restricted to English-language only sources, studies that looked at humans, and restricting the search terms to Title/Abstract/Keyword fields, except for ethic* which could appear in any field. This allowed us to capture sources that dealt with issues of ethics but did not necessarily use this term in the title/abstract/keywords. There were no timeframe restrictions in place. The searches were originally conducted on June 12th, 2020 and updated on August 20th, 2020. A concentrated search of the same databases was conducted on June 17th, 2020 and updated on August 20th, 2020 using the terms: (("Severe Acute Respiratory Syndrome" OR SARS OR "Middle East Respiratory Syndrome" OR MERS OR "Influenza A" OR H1N1 OR coronavirus) AND ("people who use drugs" OR PWUD OR "people who inject drugs" OR PWID OR "substance user" or "drug user")). While adhering to the same restrictions above and also restricting the search terms to the Title/Abstract/Keyword fields. This allowed us to capture sources that dealt with issues of ethics but did not necessarily use this term. AG and KR collaborated on the search strategy and shared it with the wider team (CS, MG) for comment. A total of 185 sources were identified through the database search. Bramer et al. 's (2016) de-duplication method was utilized to remove duplicate results in EndNote X9.³³ After de-duplication 142 sources remained. Search results were managed using EndNote X9. KR screened all titles and abstracts for eligibility according to the following criteria: a) sources examining SARS/MERS/H1N1/other coronaviruses; b) sources that considered people who use drugs, substance use or addiction, and service providers (health care, harm reduction, mental health, etc.); c) addressed ethical issues/used an ethics framework (e.g., public health, clinical, research ethics; including terms such as rights, morality, duty of care, etc.). KR screened all sources initially. AG subsequently reviewed any sources where there was uncertainty. KR and AG discussed these issues by phone until the uncertainty was resolved. A total of 0 sources are included in this scoping review.

For both searches, MP used Excel to chart the data across the following categories: authors, year, location, study purpose, ethical domain/framework, methods, timeframe, sample size, outcomes, relevant findings and considerations. AG confirmed the extracted data. AG, CS, MG, KR, and MP summarized and synthesized all sources of data. While we recognize that all of the studies we reviewed have ethical dimensions, we focused on those which explicitly engaged with ethical issues (normative and descriptive) as they relate to PWUD and public health emergencies, which resulted in a small sample of articles which were included in the review.

Results: Overall, few academic and grey resources discussed ethical issues related to the needs of PWUD during COVID-19 and the other public health emergencies we included in our search parameters. We discuss results from question 1 and 2:

Q1: We found three articles related to ethical issues in the continuity of care and access for PWUD.³⁴⁻³⁶ In their opinion paper, Dunlop and colleagues³⁴ identify stigma, equity, and access issues as key ethical considerations and warn about risks related to PWUD not receiving treatment for substance use and adequate COVID-19 screening and treatment. In their observational study of adapting their Adolescent and Young Adult Medicine Clinic to a telemedicine model, Barney and colleagues³⁵ note the high proportion of youth with substance use issues and point to the ethical and legal complexities, "including concerns over privacy and data security, inequity in access to technology and technological knowledge, and questions regarding effects on the doctor-patient relationship" and call for future research and guidelines. Sharing a challenging bioethics case consultation, Sullivan³⁶ describes a clinical scenario in which a patient who used cocaine was deemed non-compliant with treatment orders related to their chronic condition. The attending physician was seeking ethical guidance about the permissibility of discharging the patient, whom they perceived as a low priority for resource allocation in the context of an anticipated COVID-19 surge, to an outpatient program despite the ethical and legal duty to provide treatment on-site. Sullivan poignantly describes this as "one of the more insidious effects of the pandemic: that the work to erode the narrative that some patients deserve health care by virtue of their compliant behavior and that those who are non-adherent don't will resurge if resources become even scarcer than they were at the end of March." We found one discussion about the use of restrictive measures related to PWUD.³⁷ In the commentary by Gold, Strous, and Appelbaum,³⁷ the authors argue it is ethically impermissible, as well as illegal, to use psychiatric orders to involuntarily hospitalize people who use drugs and alcohol for violating COVID-19 distancing requirements.

We found one article which addressed professional ethics considerations.³⁸ In their analytic paper, Bansal and colleagues³⁸ identify ethical dilemmas which are intrinsic in all rationed care, and although they do not address PWUD as a clinical population, they consider that the strain

of the pandemic may result in care providers using substances (including self-medicating) which may impact their ability to practice. Finally, we found an operations manual COVID-19 management in housing produced by Vancouver Coastal Health which recognizes the intersections of homelessness and substance use and identifies a series of principles and ethical considerations which broadly call for measures to increase social justice (e.g., access to adequate health and income supports) and reduces harms experienced in health systems (e.g., by adopting trauma-informed practice and cultural safety and least intrusive measures).³⁹ Notably, access to a safe supply of drugs is explicitly listed.

Q2: Through search strategy two, we did not find any articles which met our inclusion criteria.

Discussion: Overall, the literature we reviewed is lacking in explicit ethical analyses (e.g., identification of ethical principles and frameworks) to inform decision-making about PWUD in the context of the COVID-19 pandemic and related public health emergencies. These findings are surprising considering early calls for explicit ethical reasoning in pandemic influenza.⁴⁰ We found but did not include clinical guidance relevant to PWUD (which will be discussed elsewhere) because it did not explicitly identify and discuss the ethical issues. Future iterations of guidance such as found in "COVID-19 and substance use disorders: recommendations to a comprehensive healthcare response. An international society of addiction medicine (ISAM) practice and policy interest group position paper" ⁴¹ would benefit from an explicit discussion of the relevant ethical issues. As well, while Marsden and colleagues⁴² discuss institutional review boards "fast-tracking new and amended research protocols to study the impact of COVID-19 on populations with addictive disorders," they do not discuss the ethical implications for PWUD whose status as research participants is often contested by research ethics boards and in the empirical research ethics literature.^{43,44} Historically, PWUD have been over studied and underengaged in the research process despite calls for their greater and meaningful involvement.⁴⁵

Drawing insights from discussions of past public health emergencies, we call for future research about ethical issues related to the needs of PWUD in the context of the COVID-19 pandemic along the lines of research, clinical care, legal counsel and public health interventions. First, ethical research protocols should be developed in consultation with PWUD and reflective of past guidance about issues in research design, informed consent, compensation, and community engagement.⁴⁶⁻⁴⁸ Second, research should be conducted from the perspective of PWUD and healthcare and human service providers to identify key ethical considerations that have emerged in relation to COVID-19 protocols (e.g., resource rationing, clinical triage, and treatment restrictions and modifications). Third, research should be conducted about the ethical dimensions of emergency restrictive public health measures (e.g., reduction or closure of services for PWUD) and positive measures targeted at PWUD (e.g., scale-up of safe supply)

inclusive of the perspectives of PWUD and other stakeholders (e.g., public health, clinical, health and human services, social services, and legal and policy experts). We note that despite the recent availability of a safe supply of opioids, benzodiazepines, and stimulants in British Columbia, we did not find an explicit discussion of the ethical issues.² All research involving PWUD in the Canadian context should adopt an intersectional approach that recognizes diversity and complexity along the lines of gender, ethnicity, Indigeneity, sexuality, ability, class, and health status. These and other investigations which centre the needs of PWUD are a necessary step towards developing comprehensive ethical guidance and decision-making frameworks for use by research, clinical, public health, legal, and other government decision-makers in the COVID-19 response. Communities of PWUD have produced guidance about what constitutes ethical research which is applicable in the context of the COVID-19 pandemic.⁴⁹

Conclusion: This review identified a critical gap in the academic and grey literature about ethical considerations related to the needs of PWUD during the emergency created by the COVID-19 pandemic and past public health emergencies. In the absence of COVID-19 specific resources and guidance about how to manage complex and competing ethical considerations which have, are, and will emerge as the pandemic evolves, exploratory research and dialogue is needed to ensure research, clinical care, and public health interventions are designed and delivered ethically. To develop ethical and sustainable drug policy, diverse communities of PWUD need to be engaged in the research process and in developing community-relevant ethical guidance.

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