# Changing addiction problems and care responses during and after a major crisis: Emergence of a 'new normal'

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# Changing addiction problems and care responses during and after a major crisis: Emergence of a 'new normal'

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# Editorial: Changing addiction problems and care responses during and after a major crisis: emergence of a 'new normal'

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Editorial on the Research Topic
Changing addiction problems and care responses during and after a major crisis: emergence of a 'new normal'

A major crisis can be understood as a significant societal event that disrupts the status quo in many spheres of life. Whether man-made (like revolutions, wars, or economic catastrophes) or natural disasters (like earthquakes, forest fires, or pandemics), crises are often polyphonic, with several disruptions happening simultaneously. Crises have occurred throughout the history of humanity, and the contemporary world continues to witness many, ranging from COVID-19 to wars to revolutions to natural disasters. Furthermore, crises put an enormous strain on societal resources and preparedness to mitigate their effects needs to be significantly improved and better understood. High-income countries may have relatively more resources prior to a crisis, but in the absence of crisis mitigation systems and processes, they may prove ill-prepared and still be left helpless. Lessons from Low- and Middle-Income Countries (LMIC) that have mitigated various risks over extended periods of time could thus be invaluable. This Research Topic brings together diverse research contributions on addiction in the context of crises, with a focus on both damage during and after a crisis, and the opportunities for innovation and improvement post-crisis. Collectively, these contributions begin to unpack key lessons about how addiction treatment systems at all levels—individual patients and providers, facilities, and institutions of national and international caliber—cope with and adapt to crises. They also examine the extent to which emergency solutions for providing addiction treatment services during a crisis are sustainable over time and the changes they can set in motion. Most importantly, this Research Topic shines light on empirical evidence that lifts the "fog of crisis", to highlight the experiences and implications of crisis from the perspectives of different stakeholders and to build an understanding of the reality of what has happened.

This Research Topic features 13 articles and, while they all focus on substance use disorders including opioids (Kabembo) and alcohol (Nikitin et al.), they also capture the diversity of approaches to studying addiction problems and care responses during

and after major crises in terms of methodologies, level of analysis, regional focus, and specific crises explored. Five articles report qualitative studies, three report findings from randomized controlled trials, four are based on survey research, and one reviews mixed-methods data from several sources. Of the 13 articles published in this Research Topic, six focus on HICs and seven on LMICs. However, all but one of the latter are written by HIC authors in collaboration with LMIC co-authors. This collaboration is undeniably positive but in our experience as Co-Editors who have encouraged and mentored many other LMIC authors (who sent in their ideas for a contribution), it was challenging for many potential contributors to set aside the demands of the crisis merely to complete and document academic analyses, largely because the crisis context required potential contributors in LMICs, like Mexico or Ukraine, to take on extra teaching, clinical care, and/or consultancy work to meet urgent response needs and to mitigate the escalating cost of living. Perhaps an immediate lesson to be learned is that research and timely analysis of crises need protected time through grant funding. Geographically, five articles focus on Ukraine, four on England, one on the United States, one on Zambia, one on Uganda, and one on the Western Europe region. Eleven articles investigate contemporary crises while one focuses on the aftermath of the Ugandan war a few years ago, and one article describes the status quo before COVID-19 and the war in Ukraine. From an editorial perspective, we would like to highlight three key themes in this corpus of articles.

The first key theme evident in all 13 articles is **the value of empirical research during and after the crisis**, to provide lessons for the future that are genuinely international (Sekeris et al.). Presenting evidence on how addiction treatment systems adapt to crises helps to overcome a mono-directional and inadvertently neo-colonial perspective, where practices from the West/HICs are often naively considered as universal therapeutic templates to be better rebuilt everywhere after a crisis. For example, articles by Nikitin et al. and Ponticello et al., which examine addiction treatment in Ukraine during the Russian invasion emphasize the importance of considering the impact of crises on the implementation process of OAT scale-up efforts and point to local Ukrainian-grown solutions for flexibility and responsiveness to patient needs in complex and rapidly changing environments. Similarly, Dellamura et al. take a step further and suggest that imposing on Ukrainian addiction treatment providers a system of accelerated performance indicators based on the recommendations of the Global Fund and other international authorities several years before the COVID-19 and war crises, without expanding the resources and addressing clinicians' concerns, increased the structural deficits in the healthcare system that the crisis exposed, while simultaneously fostering the ingenuity of healthcare workers to function in the absence of support, a crucial skill for survival under even more adverse circumstances. Describing the opioid epidemic as a man-made and avoidable crisis, McDonald et al. point to the role of transparency, accountability and the need for robust scientific research during crises.

The second thread running through all the articles is **the magnitude of the resilience of addiction care** in LMICs and HICs in the face of crisis, while also highlighting the limitations and costs of this resilience in terms of the burdens shouldered by individuals (patients and healthcare workers), families and caregivers, and facilities and care systems. As described in this Research Topic, across all contexts studied (from rural England to war-affected communities in Ukraine to post-conflict refugee camps in Uganda to an urban Californian community during the COVID-19 pandemic), addiction care was already, operating under conditions of overstretched resources pre-crisis (Makoha and Denov; Fstkchian et al.; Kabembo; Scott et al.). However, while the need for care intensified during the crisis and each context provided evidence of individual and collective ingenuity and adaptability that allowed, by and large, addiction care to be maintained for vulnerable patients, the uncomfortable question raised by the articles is the risk of working beyond capacity becoming solidified as the new normal. When the new normal is the crisis itself, then the context is permanently dangerous and unpredictable, and with the risk that resources will be permanently inadequate.

The final key theme to emerge from the Research Topic is **the value of local knowledge** (and the local experts who embody and practice it) as the principal ingredient **in crisis mitigation in addiction care**. No practice (e.g., allowing take-home doses of methadone for stable patients, or the use of telehealth) could prove universally sufficient without being promptly adapted and tailored to the local context, and articles by Galvez et al. and Ponticello et al. detail how this is being done during the war in Ukraine in prisons and in the community (Mazhnaya et al.). However, evidence from rural English communities during the COVID-19 crisis suggests that these practices need to be applied with caution (Scott et al.), both due to the relative digital illiteracy of some of the most vulnerable patients (Gilchrist et al.), and because the elimination of regular contact with the provider deprived such patients of the essential touch-base care points that gave them social support and medical advice (Campbell et al.).

In sum, we present this Research Topic as a valuable start to examining how addiction problems and care responses change during a major crisis and we call for continued work on this topic. First, we see extensive opportunities to integrate diverse evidence from different regions and across historical periods. More empirical and longitudinal research is needed to understand, for example, the responses to COVID-19 or the war in Ukraine (to take just two crises) over time, and to assess the long-term effects of any mitigation measures on individuals, facilities, and the national addiction care system. Systematic reviews of adaptations to addiction care during crises, as well as analyses of large international datasets, would be a crucial addition to the extant evidence base. Second, several article proposals that did not make it into this Research Topic have raised our awareness of gaps in knowledge that still need to be bridged. These concern geographic regions (e.g., Central Asia and Latin America) that remain unexplored in the current Research Topic, as well as substantive topics (e.g., drug trade/supply responses to crises; or the digital technologies in addiction care during and after crises) that still require attention. From conversations with potential authors, we realized the potential importance of articles that analyze the decision-making of local or (inter)national addiction care authorities during a crisis about how to re-organize and

change patient care, in the absence of readily available guidelines for such decisions: these result in great uncertainty, multiple risks, and a heavy burden of responsibility if anything goes wrong, and this needs to be better understood, described and investigated. It is our hope that such research will be undertaken and featured in future Research Topics. Finally, we see this Research Topic as one of the first steps toward the genuine de-colonization of international guidelines for the provision of addiction care during crises. Evidence from different contexts needs to be examined and brought together to allow both HICs and LMICs to benefit from mutual learning.

It has been a privilege to guest edit this Research Topic and we thank all the contributors for their insightful research. We believe that this Research Topic can be useful to readers in academia, clinical care, public policy, and wherever there are work-related interests and/or lived and living experiences that involve addiction care, and we hope that this will provoke further reflection and discussion on what crises can teach us if we are willing to learn.

## Author contributions

JS: Conceptualization, Investigation, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing. AD: Conceptualization, Methodology, Project administration, Writing – original draft, Writing – review & editing. HS: Conceptualization, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. JR: Conceptualization, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# The effect of the COVID-19 pandemic on the prescribing of opioid and opioid use disorder medications within an academic medical center in California

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**Introduction:** The COVID-19 pandemic impacted healthcare operations affecting many patients with chronic pain and substance use disorder. Our study aimed to evaluate the effects of the COVID-19 pandemic on opioid and opioid use disorder (OUD) medication prescribing practices within a large academic health system in southern California.

**Methods:** This retrospective cohort study included patients who received a prescription for chronic opioids or therapy for OUD between November 1, 2019 and September 1, 2020. The date range was divided into five specific time periods during the pandemic: November through December 2019 (pre-COVID and reference period), January through February 2020 (early COVID), March through April 2020 (policy/guidance change period), May through June 2020 (early post-guidance period), and July through August 2020 (late post-guidance period). The primary outcome was change in morphine milligram equivalents (MME) prescribed. Secondary outcomes included encounter type, mode of prescription ordering, naloxone prescriptions, and urine drug screen obtainment.

**Results:** The cohort included 100 patients divided among the designated time periods. Seventy-percent of patients received opioids for chronic non-malignant pain and 10% received therapy for OUD. Although there were numerical increases in MMEs prescribed, no significant changes were seen in the MMEs prescribed at any timepoint relative to the pre-COVID timeframe despite reduced in-person visits, increased video and telephone encounters and increased electronic prescription utilization. Subgroup analyses of those with chronic pain only or OUD had similar findings.

**Conclusion:** It appears that, generally, prescribing practices were sustained despite the various phases of the pandemic including transitions to and from telemedicine.

# Introduction

As of August 2022, Coronavirus Disease 2019 (COVID-19) has led to over 90 million cases in the United States (US) and over 1-million deaths (1). The pandemic has affected many aspects of our nation's infrastructure including the labor force, mental health, and healthcare (2–5). Healthcare institutions have experienced significant operational changes as states and local governments adjust a range of policies to reduce COVID-19 transmission (6). These measures have included canceling or postponing elective procedures, limiting outpatient visits, converting to telemedicine for non-urgent health services, and enacting exemptions for prescribing and refilling controlled substances (7–10). The National Bureau of Economic Research found a 40% decline in outpatient visits from the first week of March to early April 2020 (11). Delays or cancelations of healthcare visits may have deleterious effects on patient health outcomes. Patients living with chronic pain and OUD are particularly susceptible to adverse outcomes as their care is dependent upon access to in-person services, such as physical therapy, interventional procedures, and initiation of specific medications (12–15).

While prescriptions for controlled substances issued electronically must generally be predicated on an in-person medical evaluation, the federal Controlled Substances Act contains exceptions during a public health emergency. Thus, on January 31, 2020, when the Secretary of Health and Human Services (HHS) declared COVID-19 a nationwide public health emergency (16), prescribing controlled substances via telemedicine without an initial in-person visit was permitted. Additionally, the Centers for Medicare and Medicaid Services (CMS) expanded telehealth services, allowing providers to be reimbursed at the same rate as an in-person visit (17). In March of 2020, the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Drug Enforcement Agency (DEA) released guidance documents to help providers navigate prescribing controlled substances, including OUD medications, amid the pandemic (18). Several governing bodies provided guidance to managing patients with chronic pain and OUD during the pandemic (18–23). Soon after, on April 16, 2020, CMS issued guidelines to "Opening Up America Again," allowing for state and local governments to resume in-person nonemergent and non-COVID care if certain criteria were met (24). Specific to California, beginning in May 2020, the governor signed several executive orders, one of which informed local health jurisdictions that they may gradually reopen with modifications (25). Considering the many direct and indirect ways healthcare administration was impacted by the pandemic, the objective of this study was to evaluate the effects of the COVID-19 pandemic on opioid and OUD medication prescribing practices. Previously published studies found significant decreases in the prescribing of these medications among opioid naïve or new patients, who appear to be vulnerable to reduced access to care (5, 26). We aimed to determine how such prescribing is affected within a large academic health system amid a public health emergency among individuals with chronic opioid or OUD prescriptions.

# Methods

## Procedures

This study was approved by the local Institutional Review Board and was a retrospective cohort study that included patients at least 18 years old who received an outpatient prescription for an opioid or OUD medication between November 1, 2019, and September 1, 2020. The study institution provides an average of 1 million outpatient visits per year. We excluded patients on opioid or OUD therapy for fewer than 3 months and those prescribed opioids for post-surgical pain or after an emergency department discharge. Data inquiry was made for all outpatient opioid prescription orders including fentanyl, hydrocodone, hydromorphone, morphine, oxycodone, oxymorphone, and tapentadol as well as OUD medications: buprenorphine (with or without naloxone) and methadone. A random number generator was used for probability sampling to screen orders for study inclusion (Figure 1). Most orders were excluded as they were short-term opioid prescriptions prescribed after a surgical procedure. Additionally, identical orders for the same patient within the same time frame were nullified and use of the random number generator was repeated for the next selection.

Included patients were distributed among five different timeframes, depending on which timeframe they received an opioid prescription. The different time periods represent the different phases of the pandemic. Group 1 represents individuals who received a prescription(s) in November or December 2019, which is designated as the pre-COVID time period before the public health emergency was announced and serves as the reference group to which all other groups are compared. Group 2 represents patients who received a prescription(s) in January or February 2020 and is designated as the early COVID timeframe when the public health emergency was announced but policies and guidance documents were not implemented or released. Group 3 represents patients who received a prescription(s) in March or April 2020 and is designated as the policy change period when stay-at-home orders were enacted, outpatient services were suspended, and policies regarding prescribing practices were implemented. Group 4 are patients who received a prescription(s) May or June 2020 and is designated as the early post-guidance period as it represents the time period after aforementioned policies were implemented and when guidelines were released regarding reopening of outpatient and non-urgent medical services. Lastly, Group 5 are patients who received a prescription(s) in July or August 2020 and is designated as the late post-guidance period representing months after policy changes occurred and outpatient services began reopening. Of note, if individuals had medication orders across the time frames, they were included in each group for which they had an order.

The objective of this study was to evaluate the effects of the COVID-19 pandemic on opioid and OUD medication prescribing practices within an academic medical center in southern California. The primary outcome was change in morphine milligram equivalents (MME) defined as the difference between daily MME prescribed to the patient before the respective timeframe and the daily MME of the last prescription ordered in that same timeframe. Secondary outcomes included encounter type (in-person, video, telephone, or refill request encounters, where a prescription was predicated on a message or phone call from the patient requesting a refill), mode of prescription ordering (electronic, print, or both), naloxone prescriptions, and urine drug screen (UDS) obtainment. Outcomes of groups 2–5 were compared to the reference group; group 1.

## Statistical analysis

For descriptive statistics, categorical variables were reported as numbers and percentages while continuous variables were reported as mean ± SD or median with range, depending on the presence of
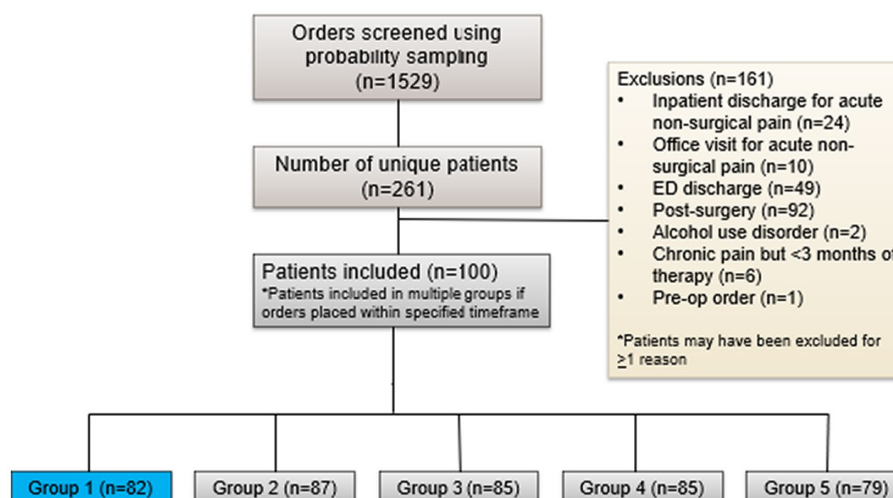
**FIGURE 1**
The number of patients screened for inclusion in the study and reasons for exclusion leading to the final study population.

outliers in the data. The mean change in MMEs between the groups was compared with a one-way ANOVA test. Secondary outcomes were compared with a Chi-square test except when comparing medians, for which a Kruskal-Wallis test was utilized. Sub-group analyses were conducted for the primary outcome among individuals with chronic pain only, OUD only, and individuals who received a prescription in group 1 plus groups 2 through 5. For the latter subgroup, a mixed model's analysis was utilized to follow individuals across different timepoints and compare the mean difference in MME in each group using group 1 as the reference point. Standardized residual plots were used to assess for outliers. Due to multiple testing, these values of $p$ are adjusted for the alpha error inflation using Bonferroni corrections. IBM SPSS Statistics for Windows (Version 27.0) was utilized for data-analysis.

## Results

A total of 100 unique patients were included. Most patients (approximately 65%) were female with a mean age of 57 years. The most common indications for opioid prescriptions were chronic non-malignant pain syndromes with over half of the patients reporting severe pain ($\geq$7 out of 10). The majority of clinicians were in primary care clinics (about 60%) and most prescribed short-acting opioids as needed (about 64%). More than half of patients in each group were concomitantly taking non-opioid pain medications including topical analgesics, anti-epileptics, and other medications used to treat neuropathy. Greater than 40% of patients in each group were also taking antidepressants, and about 10% had a concurrent benzodiazepine. Almost all patients (94%) were insured during the time of their encounter, though over one-quarter were unemployed. No significant differences in baseline characteristics were observed in each group relative to group 1 (Table 1).

For the primary endpoint, a numerical increase in mean daily MMEs was prescribed in groups 1 (11.3 ± 83.4), 3 (26.3 ± 102.0), and 4 (31.6 ± 140.4) and a mean decrease in daily MMEs was prescribed in groups 2 (−9.3 ± 79.4) and 5 (−10.9 ± 66.5), but no significant changes

were observed relative to group 1 (Figure 2A). In a subgroup analysis including individuals consistently seen by their provider through the pandemic [patients in group 1 who also had prescription(s) in the other time frames], the pattern of increased MMEs in groups 3 and 4 and a decrease in MMEs in group 5 was consistent with the original analysis (Figure 2B). However, the findings were similarly nonsignificant. Among patients with OUD, a significant decrease in MMEs was observed between groups 1 and 2 (166 ± 256.3 vs. -122.6 ± 178.2; $p$ = 0.014) with no other significant differences in prescribed MMEs and similar overall trends to the primary analysis (Figure 2C). When evaluating the 73 (90%) individuals with chronic pain only, an uptrend was seen with MMEs prescribed in group 3 (Figure 2D). In contrast to other analyses, group 2 followed an upward trend in MMEs and group 4 trended downward.

In-person visits significantly decreased and telephone and video encounters increased with the exception of group 2 where there was no difference in the number of video visits, relative to group 1 (both 0%). No difference was seen in refill request encounters nor naloxone prescribing. Providers prescribed controlled substances electronically significantly more as time passed through the pandemic and there was a significant decrease in UDS obtainment at each visit (Table 2).

## Discussion

No statistically significant changes were observed in MMEs prescribed during various periods of the pandemic. Our results are similar to a recent study that evaluated the effect of the COVID pandemic on the prescribing of opioid analgesics and buprenorphine for OUD and found no changes in total MMEs or units of buprenorphine prescribed among existing patients, defined as those who received a prescription for said medications in the past 365 days (26). We also evaluated changes in MME prescribing per individual rather than total MMEs across the population reflecting a more patient-centered approach than what was previously published.

TABLE 1 Baseline characteristics.

| | | Groups | | | | | p value |
|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | |
| | | n =82 | n =87 | n =85 | n =85 | n =79 | |
| Gender | Male | 30 (37.0) | 31 (36.0) | 27 (32.1) | 31 (36.9) | 27 (34.6) | 0.963 |
| | Female | 52 (63.0) | 56 (64.0) | 58 (67.9) | 54 (63.1) | 52 (65.4) | |
| Age, mean ± SD | | 57.5 ± 16.3 | 56.9 ± 16.2 | 57.0 ± 17.8 | 56.8 ± 16.2 | 57.8 ± 16.6 | 0.994 |
| Post-visit Rx day supply, median (range) | | 30 (3–90) | 30 (4–90) | 30 (5–90) | 30 (5–90) | 30 (7–90) | 0.198 |
| Verbal PRS* | No pain (score 0) | 9 (16.4) | 8 (13.6) | 9 (16.4) | 4 (7.5) | 5 (10.4) | 0.939 |
| | Mild (score 1–3) | 4 (7.3) | 3 (5.1) | 4 (7.3) | 3 (5.7) | 2 (4.2) | |
| | Moderate (score 4–6) | 14 (25.5) | 18 (30.5) | 12 (21.8) | 12 (22.6) | 12 (25.0) | |
| | Severe (score ≥ 7) | 28 (50.9) | 30 (50.8) | 30 (54.5) | 34 (64.2) | 29 (60.4) | |
| Indication | Chronic non-malignant pain | 58 (72.5) | 58 (68.2) | 60 (72.3) | 60 (72.3) | 58 (75.3) | 0.994 |
| | Cancer related pain | 15 (18.8) | 18 (21.2) | 15 (18.1) | 14 (16.9) | 13 (16.9) | |
| | Opioid use disorder | 7 (8.8) | 9 (10.6) | 8 (9.6) | 9 (10.8) | 6 (7.8) | |
| Control Substance Type | Scheduled | 9 (11.1) | 12 (14.1) | 10 (11.8) | 13 (15.3) | 13 (16.5) | 0.882 |
| | Short-acting PRN | 54 (66.7) | 58 (68.2) | 51 (61.4) | 53 (63.1) | 48 (61.5) | |
| | Scheduled + PRN combined | 18 (22.0) | 15 (17.2) | 22 (26.5) | 17 (20.2) | 16 (20.3) | |
| Concomitant medications | NSAIDs | 17 (22.1) | 20 (24.4) | 19 (23.5) | 20 (25.3) | 23 (31.5) | 0.718 |
| | Anti-depressants | 35 (45.5) | 38 (46.3) | 40 (49.4) | 40 (50.6) | 35 (47.9) | 0.966 |
| | Tramadol | 1 (1.3) | 3 (3.7) | 2 (2.5) | 3 (3.8) | 3 (4.1) | 0.842 |
| | Muscle relaxants | 22 (28.6) | 24 (29.3) | 22 (27.2) | 27 (34.2) | 23 (31.5) | 0.888 |
| | Non-opioid pain meds | 45 (58.4) | 20 (35.1) | 47 (58.0) | 49 (62.0) | 41 (57.7) | 0.221 |
| | Z-Hypnotics | 3 (3.9) | 3 (3.7) | 4 (4.9) | 4 (5.1) | 3 (4.2) | 0.990 |
| | Benzodiazepines | 6 (7.8) | 8 (9.8) | 9 (11.1) | 8 (10.1) | 7 (9.6) | 0.971 |
| Provider Specialty | Behavioral health | 5 (6.1) | 5 (5.7) | 6 (7.1) | 8 (9.4) | 5 (6.3) | 0.998 |
| | Primary care | 50 (61.0) | 55 (63.2) | 51 (60.0) | 54 (63.5) | 50 (63.3) | |
| | Pain/Palliative care/PM&R | 20 (24.4) | 19 (21.8) | 20 (23.5) | 16 (18.8) | 21 (26.6) | |
| | Other | 6 (7.3) | 7 (8.0) | 7 (8.2) | 6 (7.1) | 2 (2.5) | |
| Co-morbidities | Trauma | 6 (7.9) | 6 (7.5) | 7 (8.6) | 6 (7.8) | 5 (6.9) | 0.997 |
| | Mood disorder | 38 (50.0) | 41 (50.6) | 42 (52.5) | 39 (50.0) | 38 (52.1) | 0.997 |
| | Psychotic disorder | 5 (6.5) | 8 (9.8) | 8 (9.9) | 8 (10.1) | 7 (9.6) | 0.932 |
| | Anxiety disorder | 29 (37.7) | 31 (37.8) | 32 (39.5) | 31 (39.2) | 29 (39.7) | 0.998 |
| | Suicidal ideation | 3 (3.9) | 4 (4.9) | 5 (6.3) | 5 (6.4) | 6 (8.3) | 0.832 |
| | Renal impairment | 6 (7.9) | 4 (4.9) | 5 (6.3) | 4 (5.1) | 4 (5.5) | 0.938 |
| | Liver impairment | 3 (3.9) | 3 (3.7) | 2 (2.5) | 2 (2.6) | 4 (5.5) | 0.863 |
| Employment | Employed | 19 (48.7) | 19 (48.7) | 22 (52.4) | 20 (50.0) | 19 (52.8) | 0.998 |
| | Unemployed | 10 (25.6) | 12 (30.8) | 12 (28.6) | 12 (30.0) | 9 (25.0) | |
| | Retired | 6 (15.4) | 5 (12.8) | 6 (14.3) | 4 (10.0) | 6 (16.7) | |
| | Disability | 4 (10.3) | 3 (7.7) | 2 (4.8) | 4 (10.0) | 2 (5.6) | |
| Health insurance | | 71 (92.2) | 75 (91.5) | 76 (95.0) | 74 (94.9) | 70 (95.9) | 0.732 |

This table provides the comparison of baseline characteristics among patients in each of the five time periods

All values listed as N (%) unless otherwise noted. MME, morphine milliequivalents; OUD, opioid use disorder; PM&R, physical medicine and rehabilitation; PRN, as needed; PRS, pain rating scale; Rx, prescription; SD, standard deviation; and TDD, total daily dose. *Not all patients had a pain score documented and percentages reported reflect total number in each group.

A numerical decrease was observed in mean MMEs prescribed in the early stages of the pandemic and during the late post-guidance period. Decreases observed among this chronic pain population could possibly be attributable to improved pain control and attempts to taper opioids early in the pandemic. Studies evaluating pharmacy claims databases found significant reductions

FIGURE 2
The difference in morphine milligram equivalents measured in each group over the five study periods. Graph **(A)** is an analysis of all patients included in the study. Graph **(B)** is an analysis only of patients who had prescription in each of the five time periods. Graph **(C)** is an analysis of patients prescribed opioids for chronic, non-malignant pain. Graph **(D)** is an analysis of patients only prescribed buprenorphine, naloxone, or methadone for opioid use disorder. MME, morphine milligram equivalents; OUD, opioid use disorder.

in the number of opioid prescriptions and individuals filling opioid prescriptions during the pandemic (27, 28). These decreases were likely due to a reduction in elective procedures and non-emergent outpatient visits, thus reducing short-term opioid prescriptions, which were excluded from our analysis. Of note, there were also differences regarding the timeframes as we investigated 2-month

TABLE 2 Secondary outcomes.

| | | Groups | | | | | p value |
|---|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 | |
| | | n =82 | n =87 | n =85 | n =85 | n =79 | |
| Encounter type | In-person visit | 62 (76.5) | 62 (72.1) | 31 (36.9) | 12 (14.3) | 12 (15.4) | **<0.001** |
| | Video | 0 (0) | 0 (0) | 24 (28.6) | 29 (34.5) | 32 (41.0) | **<0.001** |
| | Telephone | 1 (1.2) | 2 (2.3) | 31 (36.9) | 25 (29.8) | 19 (24.4) | **<0.001** |
| | Refill request | 41 (50.6) | 42 (48.8) | 44 (52.4) | 43 (51.2) | 42 (53.8) | 0.977 |
| | In patient discharge | 4 (4.9) | 6 (7.0) | 3 (3.6) | 5 (6.0) | 3 (3.8) | 0.841 |
| | Multiple visit types | 25 (31.3) | 25 (29.1) | 44 (52.4) | 29 (34.5) | 27 (34.6) | 0.150 |
| Mode of prescription | Electronic | 49 (60.5) | 53 (61.6) | 69 (82.1) | 73 (86.9) | 70 (89.7) | **<0.001** |
| | Print | 41 (50.6) | 38 (44.2) | 27 (32.1) | 17 (20.2) | 17 (21.8) | **<0.001** |
| | Both electronic and print | 9 (11.1) | 5 (5.8) | 13 (15.5) | 6 (7.1) | 9 (11.5) | 0.244 |
| Naloxone prescriptions | | 45 (57.7) | 50 (61.0) | 45 (55.6) | 51 (63.8) | 45 (60.8) | 0.853 |
| UDS at visit | | 19 (25.0) | 21 (26.3) | 10 (12.5) | 10 (12.8) | 8 (10.9) | **0.018** |

This table captures differences in encounter type, mode of prescribing, naloxone prescriptions, and obtainment of urine drug screens among the five study periods. UDS, urine drug screen. Bolding is this context is purely for formatting and readability given 4 different charts and tables within one figure.

*All values reported as n (%), unless otherwise specified.

windows of time whereas these other studies analyzed trends over a longer duration. Our approach considered specific events during the pandemic that may have influenced prescribing trends. In the late post-guidance period, modifications to stay at home orders and the reopening of different healthcare services increased availability of previously suspended non-emergent outpatient services. Access to routine visits, physical therapy, and social interactions may have improved pain control and treatment of comorbidities (including mental health conditions), reducing the need for opioid therapy. This possibly explains why the mean MMEs trended back down to pre-pandemic levels.

The numerical increases in MME observed during the months of March–June 2020 relative to the months of November–December 2019 may be attributable to the negative effects of the pandemic on mental health conditions, as mental health is intertwined with chronic pain and substance use (29, 30). Stay-at-home orders and the lack of outpatient services, such as interventional and physical therapies, may have also contributed to loss of pain control and the observed increases in prescribed MMEs as these nonpharmacologic treatment modalities play an important role in pain management (23). This potential explanation has been supported by patient-reported reasons for pain regimen changes during the pandemic that included worsening pain, reduced provider access, and increased medication use due to cancelation of physical/psychological therapy (31). Others have similarly demonstrated negative effects of social factors on pain perception and specifically that changes to coping mechanisms for pain are associated with increased medication use (32). Furthermore, social isolation may have contributed to patient deconditioning, which is also a risk factor for loss of pain control, as the population was limited in their outdoor and gym activities (23).

Additionally, the inclusion of OUD medications (buprenorphine and methadone) in the primary analysis may have led to a more exaggerated effect since these medications have a significantly higher MME relative to other common opioids used for pain management. This is supported by the subgroup analysis that included only patients with buprenorphine or methadone prescribed for OUD where the

mean differences in MMEs were much larger in magnitude. Trends observed within this small subgroup of patients with OUD were similar to the original analysis suggesting that the changes in MMEs may have been driven largely by changes in OUD prescribed opioids. The observed numerical increases in MMEs are in line with a previous study, which showed a significant increase in the quantity of buprenorphine prescribed per prescription between the months of March and May 2020 (26).

With the vast majority of our patients having health insurance and encounters with their providers in the midst of the pandemic, the overall lack of significant differences in opioid and OUD medication prescribing was likely the result of continued access to care. These findings may not be true among uninsured patients. Unemployment rates surged during this time period of the pandemic with over 20 million Americans being laid off or furloughed (2). As a result, individuals may have lost employer provided health insurance as well as a means to pay for healthcare services, resulting in a loss of access to care, gaps in care, and ability to obtain opioid or OUD prescriptions. Our study cohort only included individuals who were on chronic opioid or OUD therapy for 3 months or more, thus these individuals may have held strong patient-provider relationships with established and regular follow-up, minimizing provider hesitancy to prescribe opioids. The continuity of care was most likely attributed to the increase in telemedicine, allowing patients to maintain access to care. Lastly, published guidance documents and policy changes regarding controlled substance prescribing, in concordance with actions by local governments and health institutions, likely played an important role in ensuring congruent care to patients with chronic pain and OUD.

Similar to our findings, other health systems have also reported increased volume of virtual visits via telephone, video, or a combination between the months of March and April 2020 (33, 34). Collectively, these data and our results suggest that the pandemic may have served as a catalyst for the acceptance, and expansion of telehealth utilization.

Accordingly, with the reduction of in-person visits, obtainment of urine drug screens (UDS) at each encounter decreased significantly.

Of note, governing bodies have recommended UDS testing not be mandatory during a public health emergency (35). Active naloxone prescriptions among the cohort remained unchanged in each group. In contrast, a study using pharmacy claims data found significant reductions in naloxone prescriptions filled (28). However, these data may include new patients prescribed opioids rather than only those with chronic opioid prescriptions for pain.

Our study was limited by a small sample size as evidenced by the large standard deviations observed in our results. Given the small number of patients with OUD, independent evaluation of this population may better elucidate the impact of the pandemic on these patients as well as inclusion of our affiliated federally qualified health center, which offers medication assisted treatment and may have been responsible for more of the prescribing during this time. Documentation in the electronic medical record system may be incomplete or inaccurate as what was prescribed may not reflect what was taken by the patient. Furthermore, worsening of substance use, drug overdoses, mental health, and suicidal ideation occurred in the United States during the pandemic (4, 5). These psychosocial aspects and stressors were not specifically investigated in this study and may have impacted the prescribing practices observed. Further assessment of the association between these potential contributing factors with OUD medication and opioid analgesic prescribing is critical, as those living with chronic pain and/or OUD are susceptible to failure in therapy, worsening of mental health, and an increase in mortality related to drug overdose (4, 5).

## Conclusion

Our study provides real-world insight into the continuity of care in patients with chronic pain and OUD amidst a public health emergency at an academic medical center in southern California. We observed no significant changes in MMEs prescribed at different time points in the pandemic relative to pre-pandemic prescribing indicating successful care for this vulnerable patient population during the pandemic despite changes in the approach to care. To further understand the impact of the pandemic on patients with chronic pain and OUD, future research could focus on individual outcomes such as pain control, opioid-related hospitalizations, and OUD relapses, to provide valuable insights into patient experiences and inform clinical practice. Additionally, given the increased use of telemedicine during the pandemic, it may be beneficial to compare the financial and clinical impact of in-person and telehealth visits among patients with chronic pain and/or OUD.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving human participants were reviewed and approved by Loma Linda University Investigational Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

## Author contributions

## Conflict of interest

## Publisher's note

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# Reducing opioid related deaths for individuals who are at high risk of death from overdose: a co-production study with people housed within prison and hostel accommodation during Covid-19

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**Background:** A record number of Opioid-related deaths occurred in Northern Ireland in 2021 and it is acknowledged that the Covid-19 pandemic compounded drugs related deaths crisis. This co-production study set out to refine the design of a wearable device for Opioid users to detect and subsequently prevent a potential overdose situation.

**Method:** Purposive sampling was used to recruit people who had substance use disorders and were living in a hostel and prison during the Covid-19 pandemic. Principles of co-production influenced the study, which encompassed a focus group phase and a wearable phase. The initial phase included three focus groups with participants who inject Opioids and one focus group with workers from a street injector support service. During the wearable phase, the participant group tested the feasibility of the wearable technology in a controlled environment. This included testing the transferability of data from the device to a backend server on the cloud.

**Results:** All focus group participants expressed an interest in the wearable technology when it was presented to them and agreed, that in principle, such a device would be extremely beneficial to help reduce the risk of overdose within the active drug using community. Participants outlined factors which would help or hinder the design of this proposed device and their decision to wear it, if it were readily available to them. Findings from wearable phase indicated that it was feasible to use a wearable device for monitoring Opioid users' biomarkers remotely. The provision of information regarding the specific functionality of the device was considered key and could be disseminated via front line services. The data acquisition and transfer process would not be a barrier for future research.

**Conclusion:** Understanding the benefit and disadvantages of technologies such as a wearable device to prevent Opioid-related deaths will be critical for mitigating the risk of overdose for people who use Heroin. It was also clear that this would be particularly relevant during Covid-19 lock-down periods, when the effects of the pandemic further exacerbated the isolation and solitude experienced by people who use Heroin.

# Background

New figures from the Northern Ireland Statistics and Research Agency (NISRA) show that 213 people died because of a drug related deaths in 2021 (1). Drug-related deaths have increased from 102 deaths in 2011 to 218 in 2020 and 213 deaths in 2021.

Deaths involving Heroin, Morphine and Cocaine were the highest on record in 2020 in Northern Ireland and drug-related deaths have more than doubled in a decade (1). This mirrors a nationwide rise in drug-related deaths, which can be attributed to macro-environmental changes that began during the Covid-19 pandemic, such as increased physical isolation, the increased rate of solitary Opioid use, mental health stressors, economic uncertainty, and enhanced lethality of the drug supply (2–4). Whilst there has not been a noticeable increase in Fentanyl or Nitazines, it is clear that an increase in polydrug use including "street" and research benzodiazepines has been noted in a recent report from the Northern Ireland Alcohol and Drug Alliance (5).

The Covid-19 pandemic disproportionally impacted People Who Inject Drugs (PWID) because they are a population subject to pre-existing socio-structural inequalities such as economic disadvantage, stigma and housing inequalities (6–8). Within the population of PWID, users who are homeless and those who are recently released from prison are considered particularly at risk of an Opioid overdose (9). Information from the Street Injectors Project, Extern (SISS), who work with PWID in Northern Ireland, indicates that there has been a steady increase in the reported intravenous (IV) use of Heroin alongside an increase in the IV use of Cocaine. There has also been more emphasis on Heroin mixed with street manufactured benzodiazepines. Wakeman et al. (4) noted that people with Opioid use dependency may have sought other substances during the Covid-19 pandemic, such as alcohol and benzodiazepines, both of which potentiate overdose risk. To date, there has been limited research in this area but figures suggest that a suite of interventions is required to help reduce the number of fatalities amongst an ever-expanding Opioid problem (10).

The majority of premature deaths of PWID are preventable through Opioid substitution programs and using Opioid reversal drugs such as Naloxone (11). It is imperative that innovative interventions are sought, tested, and implemented to address the complex issue of drug-related deaths (12) and the use of technology has been identified as a means of supporting and replacing traditional interventions in various contexts (13, 14). Wearable technology has great potential in the Harm Reduction space to detect overdose, particularly when people use alone, but has been underutilized (15). A growing body of literature demonstrates the potential of digital interventions, including wearable devices, for preventing opiate overdose (2, 16–19).

Digital technologies could also assist with advancing theories of human behavior by generating opportunities to test mediators of change and identify the most potent intervention components (20, 21). Accordingly, researchers have sought new theoretical approaches to guide the use of digital technologies that enable intensive longitudinal data collection, tailoring to participants' specific needs, or delivering targeted feedback or prompts in response to changing conditions (22, 23). Well-designed and rigorously tested digital interventions, grounded in relevant behavior theories, hold exciting promise for supporting the mental and physical health needs of individuals living with opiate dependency.

In order to address existing inequalities, consultations with PWID advocacy groups are vital when designing inclusive health response to the Covid-19 pandemic (24). The co-production study described in this article focuses on working with PWID to adapt wearable technologies to prevent loss of life in highly vulnerable populations. In this context, we worked co-productively with Opioid users from relevant frontline services to obtain their views and ideas regarding the design of the technology and also to test the feasibility of wearing such a device. Whilst working co-productively with the participant group, we aimed to refine the design of a wearables device that would specifically address these current concerns by monitoring Opioid users' life sign (SPo2 and heart rate) in order to ascertain if these could be sent successfully to a back-end server housed at Manchester Metropolitan University.

# Method

## Study overview and sample

We used a two-phase approach to answer two research questions. To examine the first question, "*what are the views and ideas of a prison population and homeless hostel occupants with Opioid disorders regarding the feasibility and acceptability of the wearable device?*" We conducted three focus groups. For the second question, "*can the data from the wearables device be successfully transferred to a secure server and what is needed (if anything) to improve the mobile technology*?," we conducted a "Wearables Phase."

Both phases were guided by principles of co-production, a method of working where service providers and users collaborate to achieve a common goal. Working in this way helps refute the idea that people with lived experiences cannot take part on an equal footing with those who hold professional positions. The approach "is value-driven and built on the principle that those who are affected by a service are best placed to help design it" [(25), unpaginated]. Reflective of the co-production nature of the study we also conducted a small focus group (4 participants) remotely (via Zoom) with workers from a Street Injector Support Service (to obtain their perspectives on wearable technology in preventing Opioid overdoses).

The initial phase of the study encompassed the use of three focus groups in total with people who inject Opioids. Two were conducted face-to-face in a prison setting with people in prison; one in Hydebank College and one in HMP Maghaberry, whilst another was carried out face-to-face with service users who reside in a homeless hostel in Belfast. The number of participants ranged from 2 to 7 for each focus

group. Two experienced researchers undertook the focus groups. One group was not recorded due to the researchers not being granted clearance from prison security to use a voice recorder. On this occasion, detailed notes were taken by the researchers.

In the second stage, we assessed the feasibility of wearing the device within a sample of the homeless population. Individuals were asked to wear the device whilst in the homeless shelter (for participant protection), whilst under the supervision of the researchers. Data was collected for 6 evening sessions between 10.11.21 and 29.11.21. Participants were asked to wear the device in the communal area between 6 and 8 p.m. during which time readings were taken from the device and stored on the individual wearable.

## Recruitment

Recruitment of the study sample of people in prison was coordinated by Alcohol and Drugs: Empowering People Through Therapy (ADEPT), a community sector organization that has been contracted to work with people who have identified drug use issues in prison. The purposive sample of hostel residents was recruited via the assistance of Extern (a non-governmental organization) who have management responsibility for the workers employed in the unit situated in Belfast. Sixteen (9 female) participants who had Opioid disorders were recruited to take part in the focus groups; 12 from the prison population and four from the homeless hostel. Their ages ranged between 22 and 43 years with a mean age of 29 years. In the wearable phase, there were six participants in the hostel (2 female) with an age range of 24–53 years.

Four members of staff at Extern's Street Injector Service (SISS) were recruited through a gatekeeper at the organization. The focus group was conducted remotely (via Zoom) by an experienced researcher on the team.

## Informed consent

Issues of capacity and consent were routinely considered by the researchers involved and so they were able to identify any concerns about impaired mental capacity. Informed consent was sought at the beginning of each focus group by the researchers and each participant was asked to provide written consent after the Participant Information Sheet was read aloud to the group and all questions relating to the study were answered by the research team.

Prior to wearing the wristband for the designated 1.5–2-h period, staff checked the participant was still willing to wear the band and that informed consent was not marred by lack of capacity. The device was not used to prevent loss of life in this study. It was simply to gauge the service users' views of the practicality of wearing the device and to assess the reliability of the transfer of data to a secure backend cloud service.

## Analyses

Focus groups were transcribed verbatim and anonymised through the removal of potential identifiers. The transcripts were uploaded to NVivo 12 for thematic analysis. All personal identifiers were removed

from focus group transcripts prior to analysis to ensure that participants could not be identified, and the audio files immediately destroyed. Two members of the research team coded the qualitative data. From the codes, a series of broader themes was identified, and these form the overview of the qualitative findings.

Data from the wearables was transferred directly to a secure private server in the cloud and was monitored intermittently by a member of the research team. The transferrable data containing the two output readings (SPo2 and heart rate) did not contain any personal identifiers. After the completion of data collection, the information was downloaded from the server and analysed using Python.

# Findings 1: focus groups

## Focus groups with opioid injectors

The initial reaction from focus groups was positive, all participants expressed an interest in the wearable technology when it was presented to them. All participants agreed, that in principle, such a device would be extremely beneficial to help reduce the risk of overdose within the active drug using community. Almost three-quarters of those users taking part (11 out of 16) had at least one personal experience of overdosing whilst injecting Heroin and had been administered Naloxone on at least one occasion. Participants were asked what factors helped or hindered the design of this proposed device and their decision to wear it, if it was readily available to them.

### GPS tracking

GPS tracking was the most common concern and biggest fear noted by the service users and all respondents ($n = 16$) were concerned about the GPS system within the device and its potential to track their everyday movements. All were keen to seek clarification regarding the particulars of the GPS system, for example, when this would be activated on the device, how, for what duration and exactly what information was captured by the technology?:

> "I just wouldn't like the tracker, I don't know…I think that's dangerous… would it be tracking you all the time or just when you have an overdose?… we're always gettin' into trouble, up to all f**king sorts on a daily basis, you wouldn't want anyone to know what you're doin, or where ya are like…" (Service User 3, female).

Three (out of 16) voiced significant concerns about wearing the device when using drugs at specific locations, for example, at their dealer's house. Participants feared the GPS might be triggered when taking a 'hit' at such a location as this would attract unwanted attention to the dealer's location. In such circumstances, they explained they would be likely to remove the device before injecting:

> "What if I'm lying up in my drug dealer's flat and I've took a hit, and the thing goes off and then all these ambulances arrive, do you know what I mean …Like the ambulances will report that 'til the police and people will think I'm a rat for getting the peelers [police service]…there's people that have been left to die for less…" (Service User 1, female).

The facilitators explained the GPS tracking would only be active if an individual's blood Oxygen saturation levels dropped below 90 percent. A substantial decrease in the SPo2 level, as well as a decreased heart rate is considered abnormal and requires immediate medical attention. The participants were assured future versions of the wearable would utilize the life sign indicators on the wristband to trigger the activation of the GPS. The device would then be able to identify the location of the user at that particular time point only and share this location with Northern Ireland Ambulance Service (NIAS) so they could issue a rapid response vehicle. This significant and understandable fear of the GPS locator highlighted that the provision of accurate information regarding this function in particular was paramount in users wearing the device.

A significant number of participants (14 out of 16) raised concerns that linkage to the Northern Ireland Ambulance Service (NIAS) and response would attract unwanted attention from the police. They were unsure if they would want to take the risk of attracting attention from authorities for fear of the consequences such as being arrested or a return to prison if out on license. On the other hand, the linkage to NIAS was perceived to be essential by the majority, as it would ensure medical assistance would arrive in the quickest possible time:

> *"I think it would be useful to link it up to the ambulance service as you've like only got so much time before ya pass [die] but not if it was linked up to the police…."* (Service User 6).

### Wristband size

Over half of respondents (9 out of 16) noted the wrist size of active Opioid users is usually significantly smaller than the average person due to poor diet and sustained drug use. This was noted primarily by female respondents. Therefore, it was agreed by the participants that the wristband of the device should be designed to ensure the best fit possible:

> *"Like most of us, by the time we get really bad…our wrists are smaller, like when I'm strung out, I'm only 6 or 7 stone like, you should make the strap out of elastic or whatever…"* (Service User 5, female).

One suggestion was to have a "snap band" as a strap or alternatively make it more flexible by using elastic. One respondent however, warned not to make the strap of the device a rubber band as users might be inclined to use this as a tourniquet when injecting. All participants agreed the device should not have a resale value.

### Alarm

Participants also agreed the device should have an alarm which was activated in an overdose situation, to alert peers and/or passers-by to administer Naloxone which would be carried by the user. The alarm would consist of a loud tone as well as a voice message to administer Naloxone:

> *"Like, what if you were down an alley somewhere havin' a hit, I'll give an example, if someone was down at the* [location] *in Belfast and there's no-one around, but if someone was to walk past and that thing had an alarm, it could either be a really loud sound or a voice stating that, 'I have Naloxone on my person, please administer the*

*Naloxone, I am an Opioid user…' if you're on your own and you've overdosed, somebody needs to find ye …"* (Service User 7, female).

One respondent, who had personally experienced a number of Opioid overdoses suggested the device should also provide the user with a warning alarm when it detects early signs of potential overdose. Almost all (14 out of 16) felt an alarm on the device would be extremely useful to alert them if one of their peers was experiencing an overdose:

> *"I think it would be really good if say you were with one of your friends and they went over and it was able to alert you as well and you had Naloxone and they didn't…"* (Service User 10, male).

### "Cancel" button on device

One respondent spoke of how during his own experiences of injecting Heroin, he recovered from a near overdose situation several times and did not require any intervention. Thus, he suggested a button on the device to cancel an activation of a response from NIAS would be beneficial, not only for users but for the already overburdened ambulance service:

> *"Do ya know the way some people are that close to overdose, but they come back? Like would there be a lot of false alarms? By the time the ambulance receives the alert and arrives and you're alright and then you could've ended up getting nicked… Something to send a message that it was a false alarm would be good… otherwise we would be wasting a lot of ambulances' times, like we would be up and gone by the time they get there probably, and there could be someone else that might really need it* [ambulance]…*like maybe it could be cancelled if our heartbeat returned to normal again for at least one minute… it could maybe send a direct message, 'crisis averted'"* (Service User 12, male).

### Appearance of wearable device

All respondents agreed the wearable device should be as discreet as possible and should resemble a plain wristband rather than a watch with an interface. The purpose and function of the device should not be obvious to others as they felt most users did not want relatives/friends to know they were using Heroin. The consensus was that it should appear as a thin black strap. It was also noted the device would need to be waterproof as a proportion of the target population would often be sleeping outdoors in all weathers.

### Sense of safety

It was discussed whether the participants felt that wearing the device would provide them with a sense of safety (in that it would reduce the risk of dying from an overdose) and thus result in them taking more Heroin. The general view was that they did not use more Heroin when carrying Naloxone on their person and so did not perceive the wearing of the device would result in an increase in use.

> *"Nah, you're gonna use what you're gonna use anyway as you've got Naloxone, users carry Naloxone, ya don't use more if you've got that so why would ya use more with one of them on your wrist?"* (Service User 14, male).

## Polydrug use

Two participants questioned whether the device would be able to detect a potential overdose when under the influence of any drug or was it just specifically designed to reduce the risk of Heroin overdose. All participants stated they often used other substances alongside Heroin, the main ones being Cocaine, Pregabalin (Lyrica) and/or Diazepam 10 mg (known locally as Blues).

> *"Most of us who use Heroin ye know, like coke and blues goes side by side with it and tablets…ya know, those three things, we all do them… like we're all proper junkies"* (Service User 5, female).

Over half (10 out of 16) considered the mixture of Pregabalin and/or Diazepam along with Heroin to be the trigger for an overdose. One respondent described the consequences of her using all three drugs simultaneously:

> *"I took blues, Pregabalin and Heroin together and I collapsed… and the blood circulation stopped runnin' through my hand and now it doesn't work properly… I can't move some of my fingers, they're stuck like that…"* (Service User 4, female).

Facilitators explained the device was designed to detect a drop in the blood Oxygen saturation levels and heart rate which would be the indicator of an overdose from any substance or mixture of drugs and this would therefore still be of benefit to polydrug users.

## Benefits vs. risks

A risk identified by some was that Naloxone could be administered to a person when not actually in an Opioid overdose situation. Others ($n = 3$) described their own experiences of having overdosed and why and ultimately they felt that the benefits of the device outweighed the risks:

> *"I'll tell you why this is a brilliant idea, cause if everyone panics and runs off and is willing to leave ya, at least the device will alert someone that you're in trouble…my friend, who overdosed there in the public toilets, if she had one of them on her, someone could've tended to her but now she's dead…"* (Service User 11, female).

The fact the users could not always depend on their peers to help them in an overdose situation was the main reason why they considered the device to be particularly beneficial. Education and information regarding Naloxone and the fact it can be used to help people in an overdose and significantly reduce the need for the police intervention was deemed vital:

> *The main reason why people leave is because they don't want the police to come, so when people finally understand that by administering Naloxone, the police aren't gonna come because they're bringing the person back… then they're gonna use it… the only reason they run is because they've got warrants or because they don't want lifted [arrested] or whatever… that's why you're better off to have one them on your arm….so as you have a better chance of getting help"* (Service User 3, female).

The wearable device was considered by all respondents to be most advantageous to those who tend to "shoot up" (inject drugs) alone at home or elsewhere:

> *"If you're on your own and you overdose somewhere in a flat or outside somewhere and nobody knows where ya are, like, then it would be good so as someone could find ya…I think it would be great for someone on their own…."* (Service User 2, female).

## Focus group with workers from street injector support service

A focus group was also conducted (remotely) with staff ($n = 4$) from Extern Street Injectors Support Service (SISS) to ascertain the views of workers regarding the feasibility of the wearables device and to obtain an overview of what the protocol is in a general overdose situation. Overall, the staff considered the device to be a good idea in principle, which would be beneficial in terms of harm reduction as it would help to reduce the number of deaths within the target population. They did, however, have some concerns regarding the practicalities of the design and the use of a wearable device within the drug using community. These are outlined in detail below.

### Resale value

It was reiterated by staff that the device should not have a resale value, otherwise it would be sold or stolen. The workers noted that due to the chaotic lifestyle of some users, they would also have concerns as to whether they would lose the device and would have to be issued with a new wearable on a regular basis.

### GPS tracking

All workers envisaged concerns and fears from users that authorities could potentially tap into the GPS system on the device, track their whereabouts on a daily basis and see the locations where they go to meet their dealers and buy drugs. They also anticipated that the dealers might have concerns and paranoia regarding their clients wearing the technology, which in turn, they feared could put the users at risk. All workers agreed that rumors can circulate quickly within the drug using community and if one person were to say that the device could track the user on a regular basis, this speculation would likely spread quickly throughout the drug using community and dealers. It was suggested by the SISS workers that the provision of honest and open information as to how the device would function was vital and could be relayed to the service users via their workers and other relevant frontline services.

### Linkage with Northern Ireland ambulance service

From the workers experience, service users have had the chance to build up trust and rapport with the SISS team and on previous overdose occasions they did not respond well to the arrival of paramedics. One respondent reported that in the majority of times, when they had administered Naloxone in an overdose situation, and paramedics had arrived, the user had not allowed the paramedics to treat them as they felt that it was an intrusion.

*"They really do take offence… you know, when we bring them round with Naloxone, the majority of them will not let the paramedics work on them because they just don't want that intrusion"* (Worker 1, female).

All SISS participants agreed that it would still be beneficial to alert the ambulance service as ultimately it was the decision of the user as to whether or not they wished to be taken to hospital in the ambulance.

*"The main thing is getting an alert to a possible overdose and getting Naloxone into them and it's their decision ultimately as to whether they want to go to hospital or not, if they don't want to, and they're ok, well then their lives will still have technically been saved by the device and the Naloxone and yes it might wear off but there are other services in town, including ourselves that can monitor that"* (Worker 2, female).

### Detection of specific substance

One suggestion was that the device could be modified to detect what type of substance the user had taken to cause the overdose, for example, benzodiazepines or heroin. They felt that this would be of great advantage as they also witness a significant number of overdoses due to Benzodiazepines, Street Benzos, Cocaine and Pregabalin.

### Alert multiple sources

It was agreed by all workers that it would be beneficial to send an alert from the device to SISS and perhaps to a nominated friend of the user. This would ensure that the user would receive a quick response from whoever is within the closest proximity. The workers pointed out that as they are based in the city center and travel on bicycles, that their response time would likely be quicker than the ambulance service. They would also be able to administer Naloxone ahead of the arrival of the emergency services.

### Ambivalence of drug users

All staff expressed concern that some users may remove the device when injecting as they would not want to potentially ruin their "hit" with the administration of Naloxone. Workers stated that a significant number of their service users were not concerned whether they lived or died, and the "hit" was paramount, regardless of the consequences.

*"…the majority of them doesn't want you* [sic] *to inject them with Naloxone, so it's like that mind set where they'll think, 'well I've a device on me, that's maybe going to send a thing saying I need an injection of Naloxone, I'm gonna take it off"* (Worker 1, female).

## Findings 2: wearable phase

For the feasibility wearable phase of the research, the Withings ScanWatch was chosen as the data collection device after a thorough survey of the consumer wearable products/services available in the current markets including Apple, Samsung, Fitbit, Garmin and Huawei. Huawei band 2, although provides 24/7 SPo2 and heart rate measurement, does not provide data export out of the ecosystem. Most devices from other brands did not provide full control of the

SPo2 measurement (SPo2 measurement with other devices is triggered only during the night, while a user is sleeping). Therefore, the Withings Brand was the only product that could meet the following requirements:

1. Collect both heart rate and Oxygen saturation (SPo2) readings from Opioid users with full control of the data.
2. Collect both heart rate and SPo2 data and synchronized to a cloud service in real-time.
3. Both heart rate and SPo2 data would be stored and could easily be accessible to use for later analysis.

During the feasibility study, participants were required to wear a ScanWatch under a shared Withings Health 10 mate account. Although not having their separate accounts created, each user's data was tagged and could be identified by his/her ScanWatch serial ID. In this way, all users' data was managed by a single account, hence making the subsequent data sharing process much easier and controllable.

The ScanWatch regularly and automatically (each minute) measured the users' heart rate without requiring any user inputs. While for the Oxygen saturation readings, users did need to manually trigger the SPo2 measuring mode and hold the watch for 30 s to make sure a valid SPo2 reading is generated. This was not considered a major drawback at this stage as the aim was to test feasibility of the transferability of data to a secure server. Thus, the need to manually trigger the SPo2 reading was not an issue as the device was not being used for real-time detection of an overdose situation. Both measured data were then synchronized through Bluetooth from the watch to a smartphone device that acted as a hub and transferred all the watch data to the backend cloud service. Through the data access API provided by the data cloud service, our analyst was able retrieve the information and perform local data exploration and analysis (see Figure 1).

After all the data was retrieved for the feasibility study, an initial data exploration study was conducted with a local analysis tool kit (Python). From this exploration, we are confident to conclude that it is feasible to use a consumable wearable device for monitoring Opioid users' biomarkers remotely. The data acquisition and transfer process will not be a barrier for such studies going forward.

## Discussion

### Focus group findings

The purpose of the qualitative component from the co-production phase was to provide information on the views and experiences of Opioid users regarding the acceptability and feasibility of wearing the device to preserve life in a potential overdose situation and to capture any ideas of how best to improve the design. In doing so, this research contributed to theoretical approaches which guide the use of digital technologies that enable intensive longitudinal data collection, tailoring to participants' specific needs, or delivering targeted feedback or prompts in response to changing conditions (22, 23).

The vast majority of participants (from PWID groups and the worker group) favored the benefits of a wearable device, which significantly outweighed the risks. They seemed keen to avail of the technology as soon as it was fully developed. It was agreed that
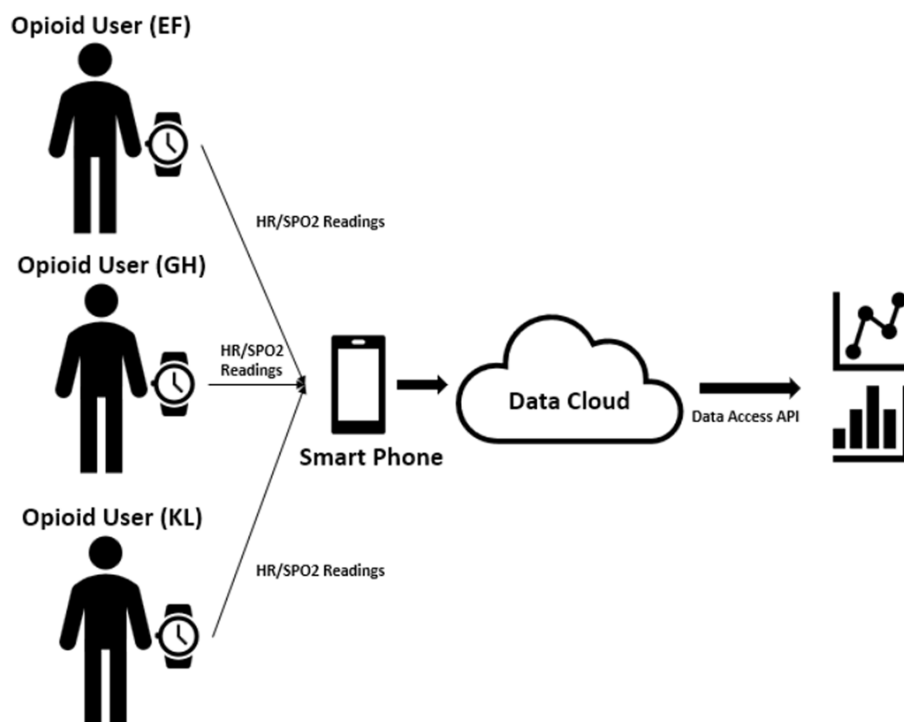
**FIGURE 1**
The data collection process and the system architecture.

information about the wearable device and how it worked needed to be readily accessible and distributed clearly to users via frontline services. This was considered key, particularly in relation to the GPS function. It was clear from the findings that users were keen to know exactly how the device would work before they would wear it. Education regarding how the device would trigger the alert was therefore crucial in order to secure buy-in and trust from the target population.

Other ideas emerging from the focus groups with PWID related to the size and flexibility of strap, the appearance of the device and the importance of having an alarm to alert passers-by as well as being linked in with a first responder service. When asked about how to best distribute the device to the target population, the consensus was that distribution should take place from a community-based facility. Users suggested the device could be readily available within a city center facility such as SISS and that they could receive a device when collecting needle packs and Naloxone. In light of this, this article adds to a growing body of literature that shows how the potential for digital interventions, such as wearable technologies, can help avoid opiate overdose (2, 16–19). Overall, SISS workers agreed that the device would be of great benefit in principle to users, particularly in terms of harm reduction. They did, however, share their views and ideas regarding the further refinement of the device for future development. Key points raised by staff included the importance of education and availability of information regarding the functioning of the device, the importance of alerting others as well as the ambulance service to ensure best response time and administration of Naloxone. SISS workers felt that their service could play a pivotal role in the initiative, as regards the dissemination of information about the technology and distribution of the device itself within the drug using community. It would also be most efficacious in responding to the alert of a potential overdose situation in the quickest time in order to administer Naloxone.

GPS tracking was the greatest concern shared in all focus groups and by both PWID and workers. In the context of Covid-19 this would be a salient area for future research. As this research was conducted in the early stages of the Covid-19 pandemic questions of tracking relating to Covid-19 were left unexplored. Initial findings around GPS-tracking from this study demonstrated concerns regarding safety about being tracked in criminalised behaviors (where participants buy drugs/where they inject/if the device is noticed by dealers). As "track and trace" became a fundamental, heavily criticised (26), part of Covid-related public health policy in the UK (27), there is an opportunity for future research to examine how PWID feel about any possible implications of being GPS-tracked in a lockdown setting (when moving around is prohibited, or moving to or from certain areas is prohibited). Further research could potentially shape PWID interest and willingness to use the device at a time when the information about their movements or location can be very sensitive.

## Wearable phase data

The heart rate and Oxygen saturations are basic metrics and can be used in conjunction with other parameters to determine the acuity of illness and as a trigger for an intervention such as the administration of Naloxone. It was therefore considered essential that the wearable device that was used in this feasibility study could capture both blood Oxygen saturation levels and heart rate. It was concluded that the blood Oxygen saturation levels and heart rate measured by the ScanWatch device had been successfully recorded and transferred to the secure cloud service which could easily be accessed by the research team. This suggests the possible use of wearable devices to provide a safety profile for patients who use drugs and is in keeping with a successful proof of concept.

As this study sought to assess whether the data (SPo2 and heart rate) recorded on the device could be successfully transferred from the device to a backend cloud server and was not testing the device in a real time overdose situation, the manual recording of SPo2 readings using the Withings ScanWatch was not a significant issue. Despite this, the researchers noted a number of shortfalls in using the Withings ScanWatch as a data collection device in general. The SPo2 reading was difficult to capture, and the readings were often inconclusive. If there was even a slight movement from the participant, the reading was deemed to be inconclusive. In addition, if the users' hands and wrists were cold, the device failed to capture Oxygen saturation levels as this resulted in a low pulsatile signal. It is quite common for users who inject to have circulatory issues which may, however, explain this issue. There were also a significant number of occasions during data collection in which the SPo2 readings were below average (between 83 and 93%). Normal pulse oximeter readings usually range from 95 to 100%.

It was noted throughout all service user focus groups that the Withings ScanWatch device was unsuitable, as it required the user to place their hand over the screen in order to obtain a reading of SPo2 in a potential overdose situation. It was agreed the user would be unable to perform this action in any potential life-threatening situation and it was unanimously agreed by participants that it would be necessary for both the readings for heart rate and SPo2 to be monitored automatically by the device without any intervention from the user.

## Conclusion

The study captured the views of Opioid users regarding the acceptability and practicality of wearing a device for PWID to detect the signs of an overdose. Those who took part offered important insight into the potential benefits and risks associated with wearing the technology within the drug using community as well as a vision of what the device should look like and how it should function in order for it to succeed. On the basis of these findings, future research could focus on the development, refinement, and piloting of a wearable device fit for purpose within the drug using community. Such findings could help address further crises if innovative digital solutions such as wearable technology are used to prevent Opioid-related deaths. Emergencies often present unexpected and uninvited ways of hastening solutions to problems, which we have wrestled with for decades. In the current post-Covid phase, we are not fully aware of how the virus may change and mutate. Currently, a number of countries are experiencing an ongoing surge of the Omicron variant. However, there is the ongoing risk of future variants of concern, which may precipitate sequential lockdowns in specific regions across the globe. As we debate the post-Covid phase and as we move into a potential endemic phase over the next 2 years (28), we are mindful that people who use drugs are still at risk of the social isolation and loneliness associated with heroin overdose and the increased barriers to seeking emergency medical care. PWID are also always at risk of further isolation in the event of the emergence of more aggressive and transmissible Covid strains. Wearable technologies for overdose prevention may help to address some of the lasting impacts of the Covid-19 crisis (29) including the increasing drug related deaths caused by overdose in the UK and on an international basis.

## Limitations

The sample size was small and not representative of the target population in general. This was partly due to the Covid-19 pandemic, subsequent restrictions and also the complexity of recruiting those from within the prison and homeless population.

## Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

## Ethics statement

The studies involving human participants were reviewed and approved by Queens University Belfast Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

## Author contributions

AC: project administration, formal analysis, writing—original draft, and visualization. SM: formal analysis, investigation, and writing—review and editing. LG: data curation, formal analysis, and writing—review and editing. UJ: formal analysis and writing—review and editing. CR: writing—review and editing. AD: investigation and writing—review and editing. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Trends in deaths following drug use in England before, during, and after the COVID-19 lockdowns

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**Aim:** This research aimed to describe how the characteristics of deaths following drug use changed during the COVID-19 pandemic in England, and how this can inform future strategy to support the health and social care of people who use drugs in future emergency scenarios.

**Method:** All deaths reported to the National Programme on Substance Abuse Deaths which occurred between January 2018 and December 2021 inclusive were extracted for analysis. Exponential smoothing models were constructed to determine any differences between forecasted vs. actual trends.

**Key results:** Following the first lockdown period in England there were significant increases in the proportion of people who died at home beyond the 95% confidence bounds of the exponential smoothing model and concurrent decreases in the proportion of people who died in hospital. Whilst the overall proportion of deaths attributable to opioids did not significantly deviate from the forecasted trend, there were significant increases in methadone-related deaths and decreases in heroin/morphine-related death beyond the 95% confidence bounds. The proportion of deaths concluded as suicide increased, as did those implicating antidepressant use. There were no changes in the proportion of deaths following use of other drug classes, alcohol use in combination with psychoactive drugs, or on decedent demographics (gender, age, and drug user status). A small number of deaths due to drug use had COVID-19 infection itself listed as a cause of death ($n = 23$).

**Conclusion:** For people who use drugs, the impact of the restrictions due to the COVID-19 pandemic was greater than that of infection from the virus itself. The health and social care strategy for these people needs to be pre-emptively adapted to mitigate against the specific risk factors for fatal drug overdose associated with future emergency scenarios.

KEYWORDS

COVID-19, coronavirus, drug-related deaths, suicide, substance use disorder, opioids, methadone, antidepressants

# 1. Introduction

The UK government response to the COVID-19 pandemic comprised a number of strategies to mitigate the impact of the disease. These included lockdown measures, whereby socialising, travel, in-person education, and non-essential business operations were restricted, and the provision of economic support for businesses and individuals (1). The first lockdown in England was initiated on March 23rd 2020 and was gradually eased from mid-June 2020 until non-essential shops, hotels and entertainment venues were allowed to reopen on July 4th 2020 (2). A second "firebreak" lockdown was planned for November 5th – December 2nd 2020, with a third and final lockdown taking place January 6th – March 8th 2021 (2).

The impact of these measures on people who use drugs were substantial, both in terms of their drug use behaviours and how they interacted with support services. Restrictions on international travel and subsequent disruptions in the global supply chain affected the availability and purity of illicit drugs (3–9), with "stay at home" messaging increasing the visibility and detection of street drug dealers by law enforcement (7). This led to illicit drug shortages, fluctuations in their prices, and increased incidence of adulterated or substituted substances (7, 9–12). Some individuals reported changes in the types of drugs that they used (7, 9, 12–15), and also in their consumption habits due to increased psychological stress, anxiety, social isolation, and boredom due to the pandemic and the resultant restrictions (13–19). Whilst reduced access to illicit drugs will have mitigated their harms, when accessed the risk of drug overdose was likely increased as individuals were often isolated and unable to determine the strength of the substance they were now using, the dosage to administer, and the frequency that they would use (13, 14, 20, 21). To mitigate against barriers to drug treatment and support services, most patients who received daily supervised consumption of opioid agonist therapies (OAT; methadone or buprenorphine) for opioid use disorder in England were switched to one- or two-week "take home" prescriptions (7, 22), and new patients were swiftly initiated onto drug treatment programs with telehealth consultations promoted (23–25). Together these measures supported the "stay at home" message for people who use drugs – who often have multiple health co-morbidities making them particularly vulnerable to COVID-19 (26, 27) – whilst also ensuring continuity of care.

It is well established that changes in access to drugs, for example due to natural disasters (e.g., Hurricane Katrina (28)) or drug policy controls (e.g., the UK Psychoactive Substances Act 2016 (29)), impact upon the number and characteristics of deaths related to drug use (30, 31). Accordingly, an evaluation is needed to understand whether the COVID-19 pandemic and resultant social and economic restrictions had positive or negative effects on the incidence and characteristics of deaths following drug use. By doing so, it will be possible to inform the health and social care strategy needed to incorporate changes which decreased incidence of fatal drug overdose, and to mitigate against the specific risk factors for increased incidence of fatal drug overdose, upon the occurrence of future emergency scenarios.

In this study we have sought to understand the impacts of the COVID-19 pandemic on deaths related to drug use in England by analysing data held by the National Programme on Substance Abuse Deaths (NPSAD). We have presented NPSAD data where deaths occurred from the beginning of 2018 until the instigation of the first lockdown in England on March 23rd 2020 (i.e., deaths which occurred prior to any pandemic restrictions), and up until the end of 2021 (i.e., deaths which occurred peri- and post-pandemic restrictions). We aimed to examine trends in decedent demographics (age, gender, drug user status), and characteristics of deaths following drug use (location of death, cause(s) of deaths, implicated drugs, manner of death, incidence of co-morbid COVID-19 infection).

# 2. Methods

## 2.1. The National Programme on Substance Abuse Deaths

NPSAD receives reports from over 85% of English coronial jurisdictions ($n = 70/82$) for deaths related to psychoactive drug use other than nicotine or caffeine (i.e., both licensed pharmaceutical medications and illicit substances). Deaths due to alcohol use alone do not qualify for reporting to the NPSAD, but cases with combined use of alcohol and psychoactive substances do. A death is referred to a coroner if it has an unknown cause, is violent or unnatural, sudden and unexplained, occurred during an operation or before the person came out of an anaesthetic, or potentially caused by an industrial disease or poisoning (32). Coronial inquest files shared with NPSAD typically comprise the Record of Inquest (including cause(s) of death), witness statements, general practitioner (GP) records, hospital records, and post-mortem and toxicology results. Toxicology tests are usually requested in cases where drug use is suspected, at the discretion of the coroner and/or consulting pathologist.

### 2.1.1. Ethics

The King's College London Biomedical & Health Sciences, Dentistry, Medicine and Natural & Mathematical sciences Research Ethics Sub-Committee reconfirmed in August 2022 that NPSAD does not require ethics review as all subjects are deceased.

### 2.1.2. Case identification

We retrospectively identified cases for analysis by extracting all deaths which occurred January 2018 – December 2021 inclusive and had been reported to NPSAD by 31st December 2022.

### 2.1.3. Data analysis

#### 2.1.3.1. Software

Analysis was carried out using IBM® SPSS™ Statistics for Windows version 27 and Microsoft Excel 365.

#### 2.1.3.2. Study periods

Data pertaining to deaths which occurred prior to the onset of the COVID-19 pandemic in England (January 2018 – February 2020 inclusive) were used to forecast expected trends in March 2020 – December 2021 using exponential smoothing models ($\alpha$=0.5), with confidence bounds calculated using a 95% confidence interval. Models were constructed for each trend in the study analysis; where not graphically displayed the actual trend did not significantly deviate beyond the 95% confidence bounds of the forecasted trend. Consistent deviations outside the 95% confidence bounds were deemed significant. All percentage figures are rounded to 0 d.p.. "Lockdown" periods were defined as those where restrictions on human socialisation and movement were enforced within England (March

23rd – July 4th 2020; November 5th – December 2nd 2020; January 6th – March 8th 2021) (2).

### 2.1.3.3. Cause of death

Circumstances that lead to death are categorised on the death certificate issued by the coroner, as follows:

Cause 1a: The immediate cause of death (and underlying if no 1b or 1c cited).

Cause 1b: Any disease/circumstances underlying Cause 1a.

Cause 1c: Any disease/circumstance underlying Cause 1b.

Cause 2: Any disease/circumstance that did not cause the death but contributed in some way.

It is not a requirement for a Cause 1b, 1c or 2 to be cited for all deaths (33). The cause of death fields were used to determine underlying cause(s) of death, and to identify implicated drugs.

## 3. Results

In this study 8,520 deaths were extracted for analysis, 54% of which ($n = 4,625$) occurred between year beginning 2018 and the day prior to the introduction of the first lockdown in the England on March 23rd 2020 as a result of the COVID-19 pandemic. The remaining 46% of deaths ($n = 3,895$) occurred from the first day of this first lockdown to year end 2021.

The number of deaths related to drug use reported to the NPSAD following the first COVID-19 lockdown did not continue to increase as per the previous and forecasted trends (Figure 1). Rather, after the mean number of reported deaths increased from 183 per month in 2019 to 193 per month in 2020, they decreased to 176 per month in 2021. Decedents continued to be predominantly male (Figure 2A), with median age at death generally increasing in line with the previous and forecasted trends (Figure 2B), although there were incidences where this fell below the 95% confidence bounds of the exponential smoothing model. The proportion of decedents who were known to have used drugs did not significantly change during any of the

lockdown periods, with the proportion of known drug users remaining consistent as opposed to the slight increase predicted by the exponential smoothing model (mean proportion of known drug users 2018 – February 2020: 56%; March 2020 – December 2021: 58%; Figure 2C).

## 3.1. Place of death

The proportion of people who died at home increased beyond the bounds of the 95% confidence interval of the exponential smoothing model based on previous trends following the first COVID-19 lockdown and remained elevated throughout 2020–21 (Figure 3). Contrastingly, the proportion of people who died in hospital decreased below the lower bound of the forecasted rate, which also persisted throughout 2021.

## 3.2. Manner and cause of death

Deaths due to drug use were predominantly concluded at inquest as accidental in nature throughout the study period (Figure 4). However, the proportion of deaths concluded as suicide following the first COVID-19 lockdown was elevated above the forecasted rate – although remained within the upper bound of the 95% confidence interval – and corresponds with the concomitant decrease in the proportion of accidental death conclusions (Figure 4). There were no significant changes in the proportion of inquests concluded as natural, open (i.e., where intent could not be determined) or homicidal in nature (Figure 4).

Opioids were the class of drug most commonly implicated in causing death throughout the study period. Following the first COVID-19 lockdown the overall proportion of deaths due to opioid use slightly decreased (2019 average of 125 deaths per month, 2021 average of 117 deaths per month,) instead of increase as forecasted. However, sub-analysis by opioid type revealed that whilst the proportion of deaths due to heroin/morphine consumption decreased, there was a concurrent increase in deaths due to methadone use (note:
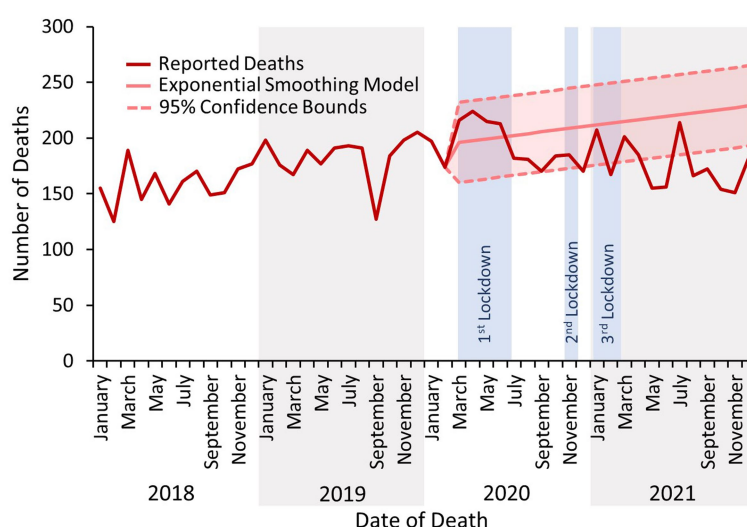


FIGURE 1
Number of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive.

**FIGURE 2**
**(A)** The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive which occurred in males. **(B)** The median age of decedents reported to the NPSAD from England from January 2018 to December 2021 inclusive. **(C)** The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive which occurred in known drug users.
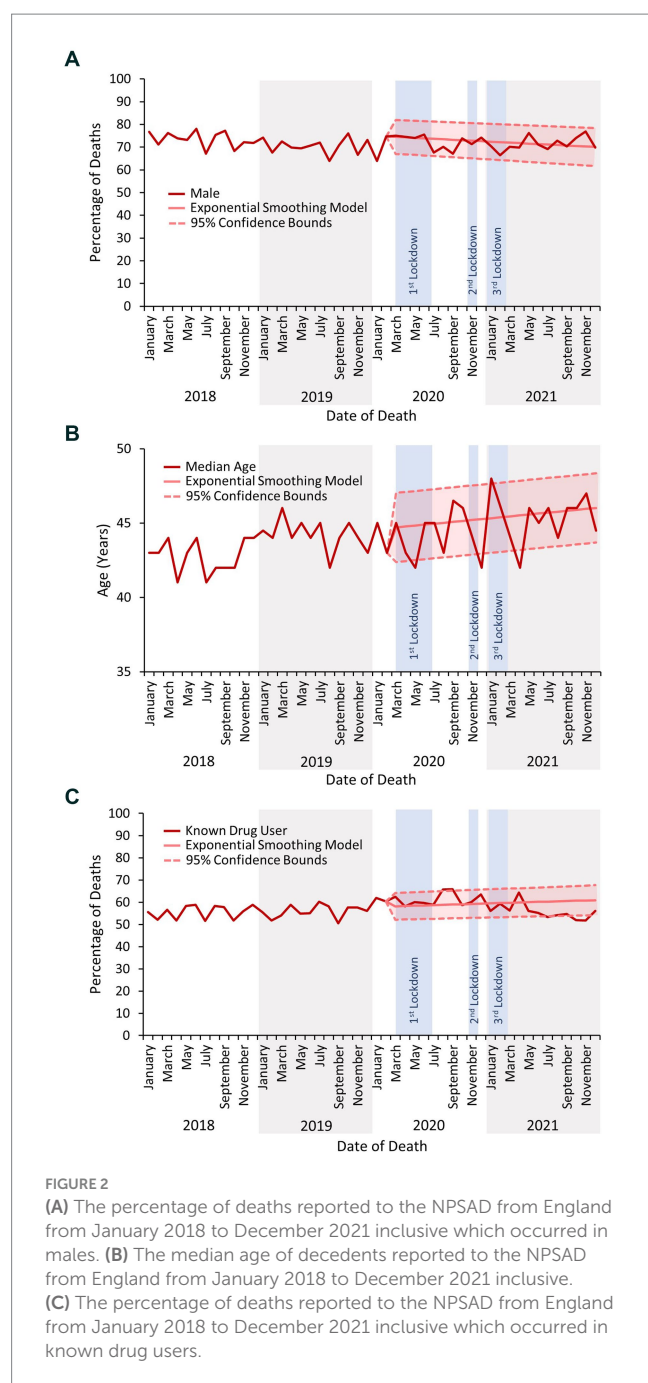
as heroin is rapidly metabolised to 6-monoacetylmorphine and morphine (34), it cannot be determined whether heroin or morphine was administered if heroin-specific markers are not tested for – as such, heroin and morphine are combined in the NPSAD database). There were no significant changes in the proportions of deaths due to use of other major opioid drugs (Figure 5A).

Stimulants were the second largest class of drug implicated in causing death, with the majority of stimulant-related deaths related to cocaine use (Figure 5B). There were no significant changes in the proportions of deaths due to stimulant drug use following the first COVID-19 lockdown, either when considered as a group or by individual substance (Figure 5B). Similarly, there were no significant changes in the proportion of deaths due to the use of other drugs

which can induce sedation, or deaths where alcohol was implicated in combination with psychoactive drug use (Figure 5C).

Deaths due to antidepressant drug use were significantly elevated above the forecasted 95% confidence bounds multiple times during and immediately following the lockdown periods (Figure 5D). Indeed, the raw number of reported deaths increased (January 2018 – February 2019 mean deaths per month: 29; March 2020 – March 2021 mean: 38; Figure 6A) although the proportion of these deaths concluded as suicide did not increase (Figure 6B). There were no significant changes in the proportions of deaths due to the use of antipsychotic drugs (Figure 5D).

COVID-19 was listed as a cause of death in 24 cases (<1% of deaths included in the study post-March 23rd 2020). In 13 of these cases COVID-19 was cited as an underlying cause of death ($n = 3$ sole underlying cause of death; $n = 10$ underlying cause of death in combination with acute drug toxicity). In the remaining 11 cases COVID-19 was cited as a contributary factor to death occurring (i.e., as a Cause 2): in 10 cases it was deemed to have contributed to death occurring due to the respiratory infection caused by the disease, and in 1 case due to exacerbation of the deceased's anxiety and depression due to the pandemic.

# 4. Discussion

Regarding deaths due to drug use, the COVID-19 pandemic was associated with an increase in the proportion of people who died at home vs. in hospital, and with changes to the characteristics of fatal opioid overdose. The proportion of deaths concluded as suicide slightly increased, as did the proportion of deaths following antidepressant use. There were no changes in the proportion of deaths following the use of other drug classes, or the gender, age, or drug user status of decedents. A very small number of deaths had COVID-19 infection itself listed as a cause of death.

## 4.1. Remote monitoring strategies are needed to mitigate risk of lone drug use

The increase in the proportion of people who died at home is understandable given the "stay at home" messaging prevalent throughout the COVID-19 lockdowns (2), a phenomenon also observed in opioid overdoses the US (35) and in deaths in the wider general population in England and Wales (36). A pre-pandemic estimate that 61% of opioid use takes place in the presence of others (37) likely decreased during and following lockdown periods (38, 39). There is recognised increased risk of death associated with lone drug use (40, 41); however, this was the precise condition enforced by the pandemic restrictions. Measures that facilitate remote monitoring, such as "spotting" via video call (42), or via wearable devices that can detect overdose pathophysiology and alert emergency services (43, 44), may mitigate the risks of lone drug use.

## 4.2. A case of could not attend or would not attend hospital?

Hospital attendance by adult patients in England during the first lockdown decreased by ~42%, with a 31% reduction in attendances
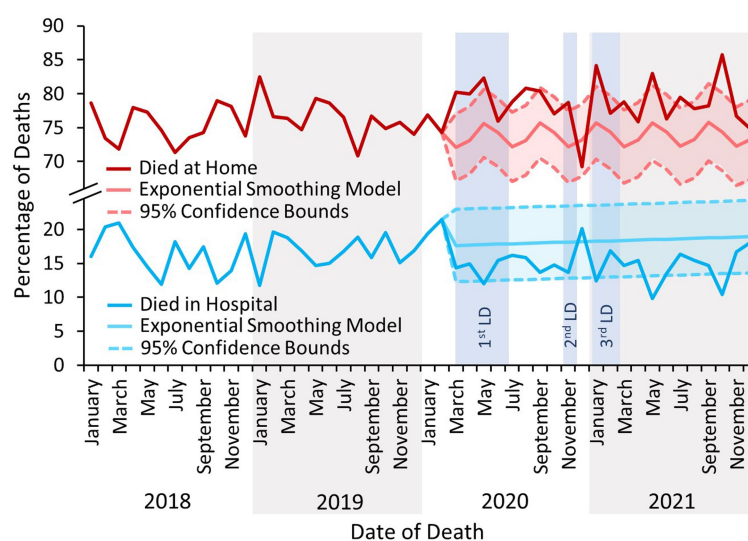
**FIGURE 3**
The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive which occurred at the decedents' homes or in hospital. LD − Lockdown. There is considerable seasonality evident in the forecasted trend for deaths in the home, with peaks around January, May, and September of each year. Whilst these months correspond to the end of the major school holiday periods in England (Christmas, Easter, and Summer) and warrant further investigation, this is outside the scope of the present study.
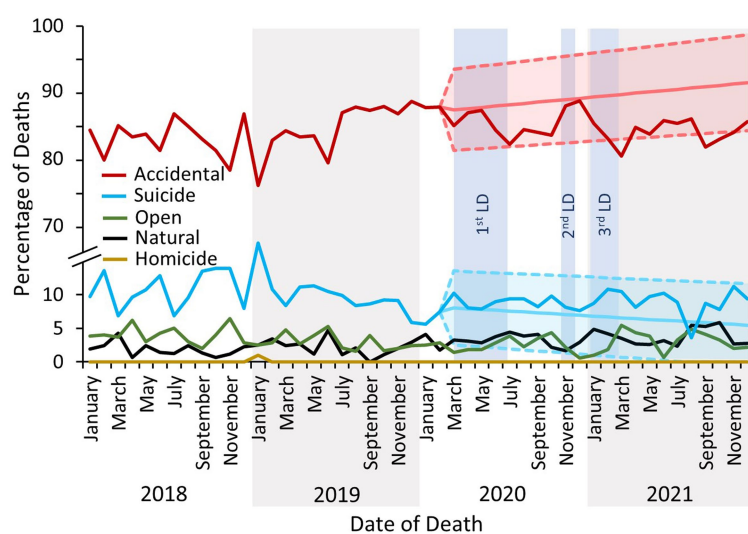


**FIGURE 4**
The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive by inquest conclusion. The exponential smoothing model and 95% confidence bounds for the accidental death trend is indicated by the light red shaded area, and for the suicide trend by the light turquoise area. Exponential smoothing models and 95% confidence bounds were calculated for open, natural and homicide trends, but were not significantly different from the actual proportion of reported deaths and are not displayed. LD, lockdown.

needing immediate attention to save life, such as drug overdoses (45). Lower rates of hospital attendance due to drug overdose could be due to increased incidence of lone drug use – whereby there is nobody present to call for help (40, 41) – compounded with increasing emergency responder times in England over the course of the pandemic (46). Furthermore, people suffering with health conditions as a result of chronic IV drug use, such as sepsis or endocarditis (26, 27), may have been hesitant to attend hospital for fear of contracting COVID-19 (45) and died without help at home. Indeed, fear of contracting COVID-19 amongst the wider population likely

contributed to more people who in a non-pandemic year may have typically died in hospital, dying at home (36).

## 4.3. People with dual diagnoses need concurrent support

Whilst the pandemic had significant impacts on mental health globally (47, 48), people who use drugs faced additional challenges including anxieties over accessing drugs, treatment provision, and
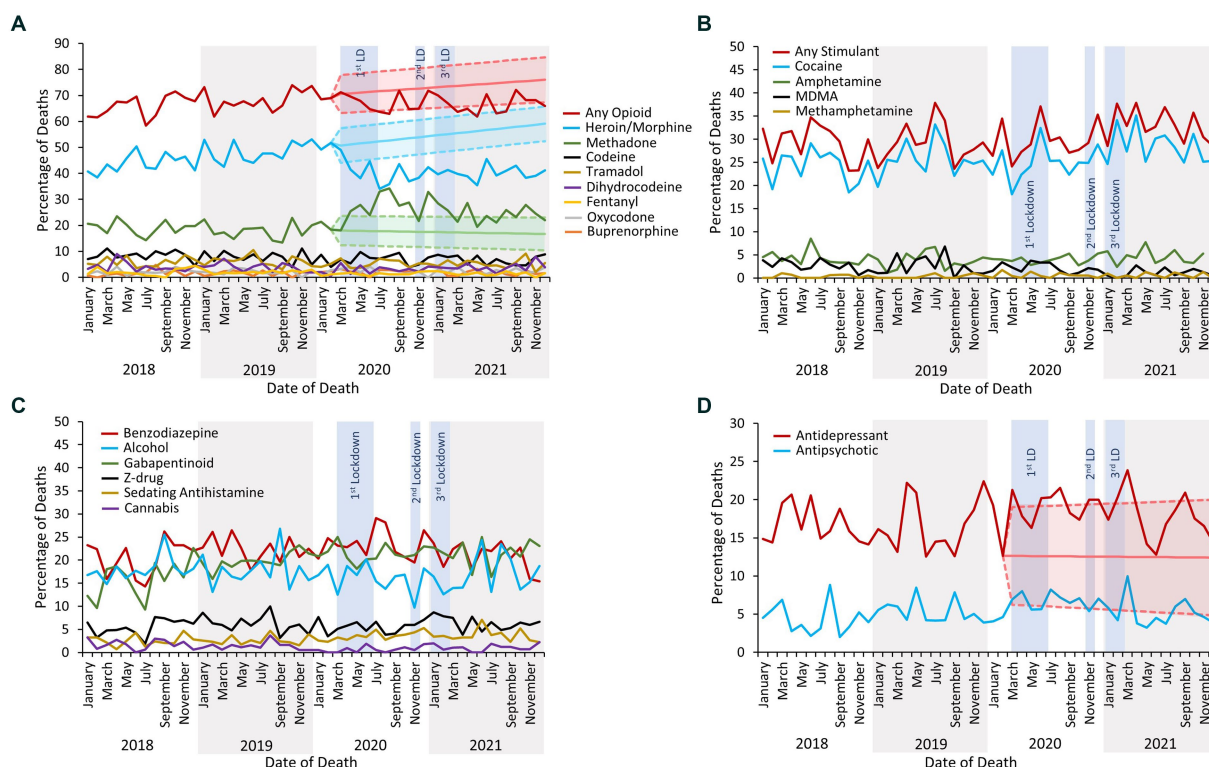
FIGURE 5
(A) The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive due to use of any opioid and by individual opioid. The exponential smoothing model and 95% confidence bounds for deaths due to use of any opioid is indicated by the light red shaded area, for deaths due to use of heroin/morphine by the light turquoise shaded area, and for deaths due to use of methadone by the light green shaded area. Exponential smoothing models and 95% confidence bounds were calculated for the remaining individual opioids but were not significantly different from the actual proportion of reported deaths and are not displayed. (B) The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive due to use of any stimulant and by individual stimulant. Exponential smoothing models and 95% confidence bounds were calculated for each trend but were not significantly different from the actual proportions of reported deaths and are not displayed. (C) The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive due to use of other sedative drugs and alcohol. Exponential smoothing models and 95% confidence bounds were calculated for each trend but were not significantly different from the actual proportions of reported deaths and are not displayed. (D) The percentage of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive due to use of antidepressants and/or antipsychotics. The exponential smoothing model and 95% confidence bounds for deaths due to use of antidepressants is indicated by the light red shaded area. An exponential smoothing model and 95% confidence bounds were calculated for the antipsychotic-related death trend but were not significantly different from the actual proportions of reported deaths and are not displayed. LD, lockdown.

support services ([13–19]). Between 40 and 70% of adults with a substance use disorder have at least one mental health disorder ([49], [50]), which likely increased in co-incidence during the pandemic ([15], [17], [19]). Indeed, this study found an increase in deaths by suicide and due to antidepressant use following the onset of the pandemic, and further evidences the need for Drug & Alcohol and Mental Health services to deliver concurrent care for people with such a "dual diagnosis" ([51]). The use of telehealth in the provision of these services during the COVID-19 pandemic generally proved successful ([52–55]) and is therefore an appropriate model for service delivery during a future emergency scenario.

## 4.4. Fatal opioid overdose characteristics changed despite no change in overall prevalence

A previous study examining only the first 3 months of the first lockdown found a significant increase in methadone-related death, with the majority increase due to deaths in people not prescribed methadone

([22]). The extended timeframe in this study demonstrates that this significant increase persisted into 2021, with a concurrent significant decrease in heroin/morphine-related death. Most patients in England receiving daily doses of methadone via supervised consumption were switched to one- or two-week "take-home" prescriptions at the beginning of the pandemic to mitigate against pharmacy closures and risk of COVID-19 infection in a vulnerable patient group, and support the "stay at home" guidance ([22]). Whilst higher volumes of drug dispensing in the community correlates with their increased misuse ([56–61]), there are many factors that need considering when interpreting this trend. These include, for example, reduced hospital attendance over the pandemic ([36], [45], [62]), although reduced access to treatment for opioid dependence does not appear to have been a factor in England ([22]). It is possible that people prescribed methadone were taking more than the intended dose due to lack of supervision, although incidence of methadone-related death in people prescribed methadone did not increase ([22]). Alternatively, people prescribed methadone could have been diverting their dose, contributing to the replacement of heroin in the drug market with methadone, as evidenced by heroin/
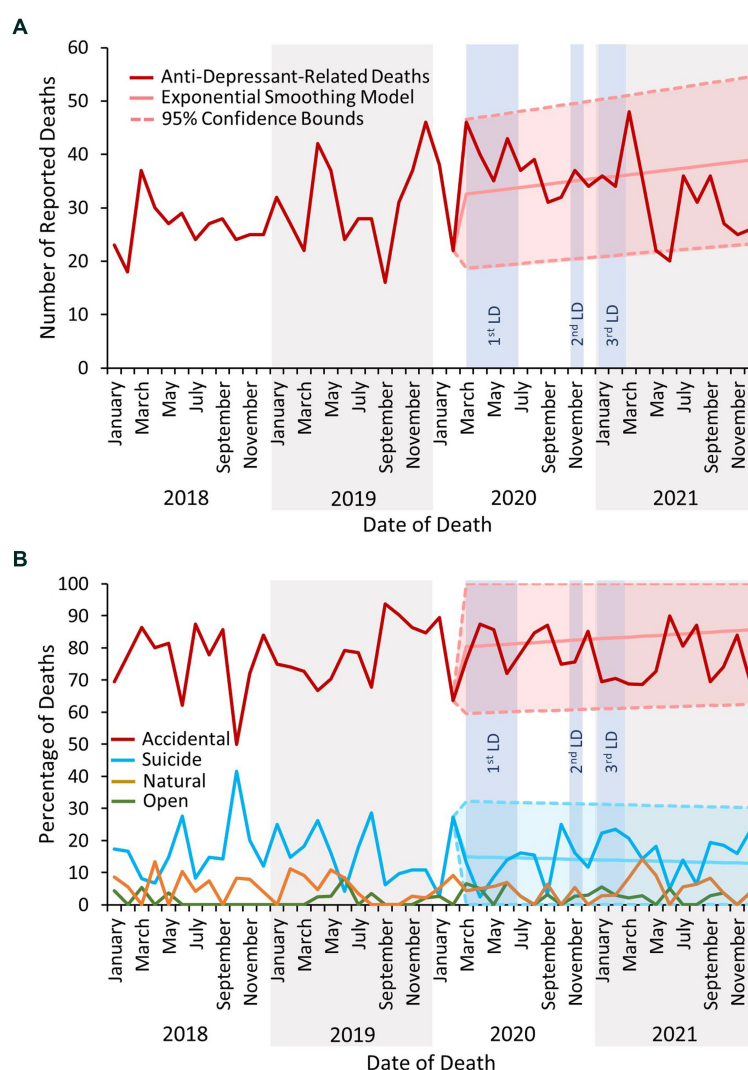
FIGURE 6
**(A)** The number of deaths reported to the NPSAD from England from January 2018 to December 2021 inclusive due to antidepressant use. **(B)** The percentage of deaths due to antidepressant use reported to the NPSAD from England from January 2018 to December 2021 inclusive by inquest conclusion. The exponential smoothing model and 95% confidence bounds for the accidental death trend is indicated by the light red shaded area, and for the suicide trend by the light turquoise area. Exponential smoothing models and 95% confidence bounds were calculated for open and natural trends but were not significantly different from the actual proportion of reported deaths and are not displayed. No antidepressant-related deaths were reported to the NPSAD which were deemed homicidal in nature. LD, lockdown.

morphine-related deaths reducing and people who use drugs reporting that heroin was less available, more expensive, and of lower quality in the UK during the pandemic (7, 63).

## 4.5. Closing of recreational spaces did not change fatalities associated with "recreational" drug use

Deaths related to "party drugs" – stimulant drugs, such as cocaine, amphetamine, and MDMA (64) – did not decrease during the pandemic despite the closing of recreational spaces and prohibition of socialising (1). However, the motivations for stimulant drug use are not always purely recreational (64), as they also offer an escape from the stressors of life (65–69), or from unbearable situations such as homelessness, abuse, or incarceration (70–75). The persistence of

stimulant-related death during the pandemic may therefore comprise a reduction in recreational "party drug" use and an increase in dependent drug use (e.g., cocaine in its "crack" form (76)).

It may be surprising that deaths following alcohol use did not change following the first lockdown, as it is well documented that alcohol use increased for many people (77–80). However, NPSAD reporting criteria is dependent upon psychoactive drug use, so any alcohol-related deaths are actually combined drug- and alcohol-related. Furthermore, most alcohol-related deaths occur due to established alcohol-related liver disease as opposed to acute alcohol poisoning (81).

## 4.6. Strengths and limitations

The strengths of this study lie in the granularity of the NPSAD data – the provision of full toxicology reports enables the drugs

involved in each death to be determined, including those with ambiguous causes of death such as "multi-drug toxicity". However, the NPSAD does not receive reports from every coronial jurisdiction in England, although the high compliance rate (over 85%) supports that the study findings can be considered representative for the whole cohort. To this end, not all deaths are referred to a coroner, and only a proportion of those referred undergo toxicology testing. Therefore, even with a 100% coronial reporting rate, data would still only reflect the proportion of deaths referred and subjected to toxicology testing. Furthermore, whilst most toxicology labs screen for common illicit drugs and licensed medications, there are variations between labs as to which substances can be detected. It is also possible that reporting jurisdictions have not concluded all inquests from deaths which occurred during the study period. Therefore, more deaths from the study period may still be reported, although as this study was performed with all deaths reported by December 31st 2022 – a year on from the end of the study period – the vast majority of 2021 deaths from reporting jurisdictions will have been received. Accordingly, the exponential smoothing model predictions made were based upon the data readily available at time of writing, and may be subject to change as and when further deaths from the study period are reported.

## 5. Conclusion

The impact of the circumstances posed by the COVID-19 pandemic was greater than that of infection from the virus itself for people who use drugs. Whilst this study suggests that deaths related to drug use in England plateaued – albeit at an all-time high (82) – following the onset of the pandemic, the factors underlying this trend evolved, and so must the health and social care strategy to prevent fatal drug overdose. The findings of this study indicate that advances in digital healthcare, such as the remote monitoring of people who use drugs to mitigate the risks of lone drug use, and telemedicine consultations to enable patient engagement with physical health, substance use, and mental health services, currently represent the best adaptive responses for future emergency scenarios.

## Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: the dataset will be available upon reasonable request from

the corresponding author. Requests to access these datasets should be directed to CC caroline.copeland@kcl.ac.uk.

## Ethics statement

The requirement of ethical approval was waived by The King's College London Biomedical & Health Sciences, Dentistry, Medicine and Natural & Mathematical sciences Research Ethics Sub-Committee for the studies involving humans because the Data Privacy Act and GDPR do not apply to personal data once a person is deceased and therefore does not require ethical review (see methods Section 2.1.1). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin because The Data Privacy Act and GDPR do not apply to personal data once a person is deceased and therefore does not require ethical review (see methods Section 2.1.1).

## Author contributions

AS collected the data, performed the analysis, wrote the first draft, and revised the manuscript. TA, DA, KR, FatA, and FarA collected the data and revised the manuscript. BW, NK, and CC conceived the idea and revised the manuscript. All authors contributed to the article and approved the submitted version.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Early disruptions to syringe services programs during the Russian invasion of Ukraine

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**Introduction:** The widespread HIV epidemic in Ukraine is concentrated among people who inject drugs (PWID), making access to sterile injection paraphernalia (SIP) like sterile needles and syringes a critical method of HIV/AIDS prevention; however, the Russian invasion has threatened to disrupt the operations of syringe services programs (SSPs), creating a risk of HIV outbreaks among PWID.

**Methods:** We conducted 10 semi-structured interviews with outreach workers from SSPs. Interviews were purposively sampled to cover three prototypic regions of Ukraine: temporarily Russian-controlled, frontline, and destination. Qualitative results from interviews were then compared against a standardized, nationwide harm reduction database.

**Results:** We found that the Russian invasion triggered both supply and demand challenges for SSPs. Demand increased for all regions due to client transitions from pharmacies that closed to SSPs, increases in illicit drug use, greater client openness to NGO support, and displacement of clients to destination regions. Supply decreased for all areas (except for remote destination regions) due to battle-related barriers like curfews, roadblocks, and Internet disruptions; diminished deliveries of SIP and funding; and staff displacement. Time series plots of the number of unique clients accessing harm reduction services showed that an initial decrease in service provision occurred at the start of the war but that most regions recovered within several months except for Russian-controlled regions, which continued to provide services to fewer clients relative to previous years.

**Conclusion:** To ensure continued scale-up of SIP and other HIV prevention services, the SyrEx database should be leveraged to serve as a streamlined harm reduction locator that can inform workers and clients of open site locations and other pertinent information.

KEYWORDS

Ukraine, war, harm reduction, HIV, syringe services programs, implementation science

## Introduction

Ukraine has the second-largest HIV epidemic in Europe, with ~360,000 people with HIV (1) and most cases being concentrated among people who inject drugs (PWID); over 1 in 5 PWID currently have HIV (2). Moreover, prevalence of PWID is substantially higher than observed throughout Europe, with 1.4% Ukrainians being PWID (3).

Syrtinge services programs (SSPs) substantially reduce risk of HIV transmission in PWID through distribution of sterile injection paraphernalia (SIP) along with disinfectant, provision of other tools for safe injection and linkage to opioid agonist therapies (4). Unlike pharmacies, which also dispense SIP, SSPs are generally free of charge and offer an array of other services like HIV screenings and linkage to addiction treatment (5). SSPs were introduced in Ukraine primarily through funding from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM), which was directed to the NGO Alliance for Public Health and their distribution of partners throughout Ukraine, including the non-occupied parts of Donetsk and Luhansk after 2013. SSPs remain a crucial component of Ukraine's national HIV response (6). Sterile syringes may also be purchased at pharmacies (6).

Harm reduction organizations in Ukraine manage SSPs at both brick-and-mortar and through mobile outreach delivery (7). These efforts are funded by the Ukrainian government and GFATM and its recipient non-governmental organizations in Ukraine (8). Prior to the 2022 invasion, over 135 harm reduction organizations received funding to provide SSP services (9). SSPs are primarily operated by outreach workers (sometimes referred to as SSP workers); outreach workers not only provide direct SSP services but also help clients navigate the prevention and treatment healthcare system (10). Scale-up of SSPs is a highly effective method for preventing the spread of HIV among PWID and between their sexual partners (4). Prior to the Russian invasion of Ukraine in 2022, over one-third of PWID without HIV accessed SSPs annually (11). The 2022 Russian invasion of Ukraine, however, markedly disrupted HIV prevention and treatment services in the country, including opioid agonist maintenance therapies (OAMT) and antiretroviral therapy (12). Site closures early in the war related to conflict and internal displacement of over 6.5 million Ukrainians have led to client and provider displacement, exacerbating disruptions to these services (13). UNAIDS estimates that nearly one-third of all people with HIV (PWH) receiving treatment experienced interruptions in their treatment since the start of the Russian invasion (14). Considering these disruptions, the conflict has likely caused similar challenges to the scale-up of SSPs in Ukraine. Sustaining scale-up is particularly important during this period, as PWID are especially sensitive to stressors like war, which in turn can result in exacerbated HIV transmission. This risk is further increased due to displacement of PWID within Ukraine and to destinations across Europe (14).

Here, we examine the extent to which SSPs in Ukraine evolved and altered their implementation strategies during the early phases of the Russian invasion. We used a previously described conflict framework that has been used to understand implementation of OAMT to analyze how different regions of the country responded to harm reduction during the early invasion (12, 15). Specifically, discontinuing OAMT has immediate adverse consequences on health, namely abstinence syndrome, overdose, and death (16), as observed in the annexation of Crimea (17), while changes in SSP delivery are likely to have immediate consequences for transmission of HIV and HCV. Moreover, disruptions in OAMT can result in increased needs for SIP. Despite these risks, SSPs have received minimal mentions in prior research on harm reduction programs in Ukraine (18, 19), especially during the war. Based on these observed research gaps, we designed this study to evaluate how SSPs in Ukraine have been affected during the war, especially based on their proximity to conflict.

Based on these findings, we then considered how scale-up of SSP services can be sustained despite war-time disruptions.

## Methods

In this mixed methods study, we employed qualitative analysis of semi-structured interviews and quantitative analysis of harm reduction data to evaluate the impact of the Russian invasion on SSPs.

## Study design

Due to the unique nature of the conflict, we analyzed data using a risk framework for Ukraine based on the proximity of areas to conflict and their relationship to OAMT delivery (15). This framework was modified, as the conflict regions have evolved throughout the war. We categorized the regional responses based on the perceived experience of SSP providers within each region as well as data on internal displacement. Based on these metrics, we categorized regions using three distinct prototype regions: temporarily *Russian-controlled*, or areas where Russian forces had taken a form of control (e.g., roadblocks or full government control) over part of the region; *frontline*, or areas that were exposed to battle-related conflict but were not Russian-controlled; and *destination*, or areas that displaced persons had settled in for over 3 months after coming from Russian-controlled and/or frontline regions. Though most destination regions were in western Ukraine (distal), others were more central, like Poltava (proximal; Figure 1).

We further categorized our analysis based on supply and demand dynamics observed by SSP providers. We derived definitions for supply and demand in the context of SSP inductively from qualitative data, and these categories served only as comparative metrics for pre-vs. post-war dynamics rather than quantitative metrics. We defined demand as client-side changes in requests for access to SIP and other SSP services. We defined supply as changes in the capacity of SSPs to provide SIP and related services to clientele.

## Sampling and study participants

From May through July 2022, we performed semi-structured interviews ($N=10$; 45 min each) with outreach workers from harm reduction organizations that manage SSPs within one of these three distinct regions. Interviews were completed in Russian by two coauthors, BMN and DJB, using video-conferencing software. Interview participants were purposively sampled based on the outlined theoretical framework to include similar numbers of participants from three conceptual areas based on proximity to the conflict: temporarily Russian-controlled, frontline, and destination regions. A semi-structured interview guide was used to direct questions, which probed participants on changes to supply and demand dynamics for SSPs following the Russian invasion of Ukraine (see Supplementary material); the interview guide evolved slightly over time. Interviews were transcribed verbatim, translated, and back-translated for content in real-time (20) and interviews were stopped when thematic saturation was achieved.

FIGURE 1
Map of Ukraine depicting sites where interviews were performed and the prototypical classification of each of these sites. Russian-occupied areas are also identified.

## Data analysis

After de-identifying translated transcripts, BMN and DJB coded the transcripts in NVivo (Release 1.7.1) and where coding differed, a third coauthor arbitrated the disagreement. Quantitative harm reduction data were provided by the Alliance for Public Health from the SyrEx Database, which is used by harm reduction organizations in Ukraine to record the quantity of clients they serve and the services they provide. Data from SyrEx did not include the quantity of SIP distributed to clients. Therefore, we applied data detailing the number of unique clients among PWID who received at least one preventive service over time as a proxy for the quantity of clients that were specifically provided SIP. We generated time series of changes to this metric over time, from January 2019 through September 2022. Time series were analyzed for the nationwide aggregate of clients as well as for each Ukrainian oblast (province) in the study to visualize whether scale-up of SSP and harm reduction services was sustained over time, particularly after 24 February 2022.

## Ethics

This study was approved by institutional reviews boards (IRBs) at Yale University and the Ukrainian Institute on Public Health Policy. Due to the low-risk nature of the study and the ongoing conflict in Ukraine, both IRBs endorsed collection of verbal consent from

participants. All identifying information described by interview participants was redacted prior to transcription. All participants were financially compensated for interviews.

## Results

We interviewed 10 SSP workers from harm reduction organizations in Ukraine, located in temporarily Russian-controlled ($N = 2$), frontline ($N = 5$), and destination ($N = 3$) regions, as per our framework. From these interviews, we observed that SIP distribution during the war was disrupted due to changes in both supply and demand of these services, with considerable variation across regions.

## Demand-side changes: "They are waiting for us like manna from heaven"

For all three prototype regions, participants reported that demand for SSPs had increased after the 2022 Russian invasion.

### Displacement of clients within Ukraine

Due to violent conflict in temporarily Russian-controlled regions, participants located in frontline and destination regions observed an influx of displaced SSP clients from the Russian-controlled regions. When conflict was pronounced throughout the country at the start of

the war, destination regions observed a rapid influx of displaced persons from frontline regions as well. In Ivano-Frankivsk, an SSP worker reported that his organization had begun supporting over 40 new clients at the start of the war; however, with violent conflict later becoming concentrated in Russian-controlled regions, many displaced persons left destination regions to return to their homes in frontline regions, including Kyiv. Within many frontline regions themselves, internal client displacement from Russian-controlled regions was also observed by participants. An SSP worker in Kaharlyk, Kyiv Oblast, indicated that the quantity of displaced clients from other regions led to a 30% increase in their overall client base. This increase in new clients due to internal displacement increased the workload of most organizations in these regions, though SSP workers generally reported that the quality of their work had not been impacted despite the increased workload.

*"Everything [in SSPs] works, just more work has been added [due to internally displaced clients]"* (Lviv, destination).

Clients were displaced from Russian-controlled regions at the highest rate, though many remained, and newly displaced clients emerged in these regions as well. While controlled by Russia, the region was locked down, and individuals were not permitted to leave. Even prior to this closure, however, many clients chose to remain due to financial barriers and/or family issues.

*"To go somewhere else, you need to have money, you need to have some kind of profession to somehow live there, to have somewhere to go"* (Kherson, Russian-controlled).

In other cases, the release of prisoners due to an influx of pardons at the start of the Russian invasion caused an increase in the number of PWID in the region seeking access to HIV prevention services, including SSPs.

*"There were amnesties for people who were serving sentences in camps and prisons. And so, those who did not have time to leave settled [in Kherson]. It's hard for them. And so, they come to us"* (Kherson, Russian-controlled).

## PWID transition from pharmacies to SSPs

Prior to the invasion, many PWID preferred purchasing SIP in pharmacies rather than obtaining it from SSPs due to distrust of these programs. In the initial weeks of the invasion, however, many pharmacies across the country closed, leading PWID who had previously relied on pharmacies to pivot to SSPs, most of which continued operating.

*"In the past, if customers could get a job, they could get clean syringes or alcohol wipes and stuff like that [from pharmacies], but now our customers are out of work. Why? Because the small businesses, including pharmacies, have closed"* (Mykolaiv, frontline).

Even as pharmacies reopened, PWID continued to rely on SSPs due to financial constraints. The costs of syringes in pharmacies increased substantially. In Russian-controlled and frontline regions,

small business closures were common and often permanent, leading many PWID to lose their sole source of income. Even after pharmacies reopened following reductions in violence, many PWID lacked the funds to purchase SIP from pharmacies, resulting in increased reliance on SSPs. In response to the war, some pharmacies hiked up syringe prices, resulting in an additional financial barrier to access.

*"It was noticed that people who used to buy syringes themselves in pharmacies started saving money and coming to us to buy syringes. Because the money they were saving, they were using it to … buy drugs"* (Poltava, proximal destination).

*"As far as I know, syringes have … doubled and tripled in price"* (Lviv, distal destination).

## Increases in illicit drug use

Loss of employment also resulted in increased stress and desperation among SSP clients, many of whom had substance use disorders that made them more vulnerable to stress (21). This stress, even for clients who kept their jobs, was compounded by persistent violence, leading many to increase injection drug use. Across Ukraine, interviewed participants hypothesized that these stressors had markedly increased with emerging trends in the drug use environment, including expanded use of synthetic cathinones (bath salts) and diphenhydramine (Dimedrol) as opioids became less available. Synthetic cathinones are injectable stimulants that are less expensive to purchase in the black market than other stimulants, while diphenhydramine is an over-the-counter antihistamine that is injected to enhance the effects of other substances, like methadone. The heightened use of these injectable substances during the war, compounded by minimal access to pharmacies, caused an increase in demand for SSPs.

*"[After the war] a lot of people have started to use bath salts. They are probably cheaper … We need to give out more [SIP than before]"* (Lviv, distal destination).

*"Dimedrol is now one of the most popular products in pharmacies… It seems like two-thirds of my clients now use Dimedrol, they say they need [larger] needles and syringes"* (Mykolaiv, frontline).

*"I honestly know that a lot of new people use Dimedrol … They're now supplementing with it because they say that our methadone is weak"* (Ivano-Frankivsk, distal destination).

Aside from wartime stresses related to violence and financial issues, some clients increased their use of substances like synthetic cathinones and diphenhydramine during the war due to disruptions in OAMT services, such as when clinics closed and/or when OAMT clinics chose to reduce dosages of OAMT out of concern for insufficient medication supply.

Limited access to methadone in clinics as well as to buprenorphine (which is generally dispensed in pharmacies) likely led PWID to resort to purchase of illegal opioids like "street methadone," another unknown opioid. Unlike methadone

prescribed in clinics, which must be consumed orally, "street methadone" is usually injected by PWID, increasing the risk of transmission of HIV and HCV. This change in access has likely increased the demand for SIP among SSP clients.

> *"[OAMT clinics] started to give them [medication] less often. They used it all very quickly and then they sat without anything. Or they had to buy street drugs, and there was no money for that. Because if they could earn extra money somewhere else in peacetime, during the war it was very hard for them"* (Bila Tserkva, Kyiv Oblast; frontline).

> *"It was impossible to get to Kyiv from Boyarka [to receive OAMT]… there were problems for a month … [The clients] switched to 'street methadone' [because of these difficulties], and 'street methadone' is of very poor quality."* (Boyarka, Kyiv Oblast; frontline).

### Evolving client sentiment

The severity of the Russian invasion, compounded by the desperation experienced by SSP clients, appeared to make clients more receptive to accept help from harm reduction organizations, despite client trust remaining limited.

> *"People are open now to any help. And they are more open to such services [like SSP], to any services that are provided"* (Chernihiv, Russian-controlled).

This change in client attitude further increased demand.

## Supply-side changes

Though SSP supply remained relatively constant in distal destination regions since the Russian invasion, it markedly decreased in both Russian-controlled frontline regions and proximal destination regions. In these areas, despite heightened demand for SIP, SSPs encountered major barriers to delivering those services to clients.

### Staff displacement

As with clients, many SSP workers from harm reduction organizations were displaced due to conflict, with many moving to destination regions in Ukraine and/or neighboring countries in Europe. Though displaced staff generally continued to work remotely, SSPs lost in-person staffing capacity, which was critical for maintaining contact with clients and ensuring that clients had continuous and sufficient access to SIP. One participant reported that each SSP worker managed a specific set of clients within their organization; the loss of in-person staff in their organization led them to lose contact with several clients.

> *"Every SSP worker has a client base. So, these are the people he's been in contact with for five to seven years. Because if we take our organization, we have people working for us for fourteen, fifteen, sixteen years … We suffer a lot when someone leaves our organization. These are people who have been working [with their clients] for a long time, who have [experience with them], and they know each other"* (Mykolaiv, frontline).

Most organizations managed to hire new staff. For newly hired SSP workers, however, harm reduction organizations needed to ensure that they were adequately trained and had built sufficient trust with clients, a process that could take up to several months. The rapid turnover of staff led to substantial strains on harm reduction organizations, which reduced the supply capacity of SSPs by extension.

> *"Four people [left]. One joined us. Well, of course, the workload on the rest of the SSP workers increased. Work has increased for the entire staff, because if earlier four more people did it, now these four are gone, and the work remains"* (Kherson, Russian-controlled).

### Curfews and roadblocks

In some Russian-controlled and frontline regions, the imposition of roadblocks, curfews, and other battle-related disruptions inhibited organizations from routine distribution of SIP. The enforcement of strict curfews forced organizations to decrease their working hours, particularly during the most violent periods of the war.

> *"Where I work, there was shelling nearby. There were troops landing nearby. And that's why we were handing out supplies very fast, two or three hours of work and that's it"* (Obukhiv, Kyiv Oblast; frontline).

For organizations operating in regions with restrictive roadblocks, they encountered major logistical barriers in their capacity to distribute SIP effectively. Prior to the invasion, most clients had accessed SIP at sites established by harm reduction organizations. With the installation of roadblocks, however, many of these sites became inaccessible to PWID who were afraid to interact with soldiers. Many clients in legal possession of methadone were arrested at these sites due to miscommunication and insufficient knowledge among soldiers. Furthermore, in Russian-controlled regions where Russia took control of the government, OAMT programs became illegal, causing additional challenges for PWID.

> *Women are afraid to walk through roadblocks… A lot of guys are afraid too. Especially if they aren't feeling well, neuroses begin … they begin to behave suspiciously at the roadblock, and then they [the soldiers] undress them, look at injection marks, and check if there are any drugs. So, such people avoid roadblocks"* (Kherson, Russian-controlled).

> *"Then moving around with methadone in your pocket, even if you had a permit, the territorial defense [staff] … didn't all know what methadone was. There were a lot of questions, there were a lot of arrests"* (Poltava, proximal destination).

> *"Clients are being seriously searched at roadblocks. Searches are done because they are suspicious persons… If a person [has been injecting drugs] for half of his lifetime, then he naturally looks suspicious"* (Kherson, Russian-controlled).

SSPs in regions with roadblocks attempted to accommodate clients by delivering SIP directly to clients' homes; however, SSP workers also encountered challenges at roadblocks while making these deliveries, further straining supply. Workers were subjected to

inspections of their vehicles, precipitating confusion when soldiers found high quantities of SIP and harm reduction supplies. To avoid confiscation of supplies and/or arrest, SSP workers carried documentation to show they were authorized to make these deliveries. Still, some soldiers were reluctant to allow passage of supplies, delaying delivery. Participants reported, however, that once SSP workers had become acquainted with the soldiers working each roadblock, deliveries became smoother.

> *"People are afraid of [roadblocks]. But anyway, you get used to it. And the military itself no longer argues with us; in the beginning, it felt odd for them. 'How is it that he is passing through with such a large load of syringes?' Well, 'I'm a volunteer'—you show the sheet and explain the situation. We confirm everything and even go to the roadblock to sort it all out"* (Kherson, Russian-controlled).

## Cellular network and internet disruptions

In Russian-controlled areas, disruptions to cellular networks and the Internet further restricted the capacity of SSPs to efficiently supply services to clients. For many harm reduction organizations, maintaining contact with clients via messaging services was a crucial method for coordinating distribution of SIP. In Russian-controlled regions, this method of communication largely vanished when Russia took government control of the region. According to one SSP worker in Kherson, Russian occupiers disabled all Ukrainian networks and required individuals in the region to purchase cellular plans from Russian providers. Most clients lacked the funds to purchase these new cellular plans. For the limited number who could, they received brand-new phone numbers that harm reduction organizations did not have recorded in their databases, preventing contact with these individuals.

## SIP and funding delivery

In Russian-controlled and frontline regions, participants reported significant disruptions to delivery of funding and SIP, restricting SSPs' capacity to provide clients with sufficient supplies. Several SSPs cut the quantity of SIP that was distributed, reportedly due to issues with SIP delivery that arose due to conflict in these and neighboring areas.

> *"In the region where I work, it turned out that we remained in Russian-controlled territory. We had blown up bridges around our town. And there was no access at all. No humanitarian aid vehicles could pass, I mean, absolutely nothing"* (Kaharlyk, Kyiv Oblast; frontline).

Other participants reported that their organizations had substantially reduced the quantity of SIP distributed during the war due to delays in delivery of SIP to harm reduction organizations. This is confirmed in Figure 1.

> *"The only issue now is quantity. We can't give more than five syringes to a person … Now it's two [per day], but before it was ten"* (Kaharlyk, Kyiv Oblast; frontline).

> *"It is clear that [42 syringes per month] is not enough for [the clients]"* (Chernihiv; Russian-controlled).

## Quantitative analysis: the SyrEx database

A quantitative analysis of the number of unique clients receiving at least one preventive service per month showed that, overall, the Russian invasion of Ukraine led to a reduction in the number of unique clients per month (Figure 2). Between September 2021 and September 2022, the number of unique clients declined by 13.3% from 112,253 to 97,349. In addition, the data for all Ukrainian harm reduction programs showed that the quantity of unique clients declined during each winter (January through March) from 2019 through 2021. This same trend was observed in 2022, indicating that the initial onset of the Russian invasion did not impact the quantity of unique clients, which was already low due to the winter-time trough. However, the *duration* of this trough in 2022 was longer than for prior years, with relatively low quantities of unique clients being recorded into April and May. This indicates likely evidence of war-related disruptions to these services.

Between oblasts where we completed interviews, we found that for Russian-controlled regions (Kherson Oblast, Chernihiv Oblast), there was a decline in unique clients during the winter that was sustained through September 2022 (Figure 3). In frontline regions (Kyiv Oblast, Mykolaiv Oblast), the quantity distributed to unique clients remained low until May but then rebounded (±5%) to the highest peak from the prior year (Figure 4). Finally, in destination regions (Ivano-Frankivsk Oblast, Lviv Oblast, Poltava Oblast), the results were mixed (Figure 5). While in Ivano-Frankivsk and Poltava Oblasts the peak quantity of unique clients was higher for 2022 than for 2021, this trend was not observed in Lviv Oblast. In Lviv, the reported quantity of clients remained low from January 2021 through September 2022, even though our qualitative interviews suggested an increased workload.

> *"More work has been added … people from other regions came to Lviv. That led us to have a lot more work"* (Lviv, distal destination).

This likely indicates that Lviv Oblast's reporting of clients into the SyrEx database was underestimated.

According to most study participants, the SyRex database was used throughout the war and served as an important source for client linkage, particularly for displaced clients. All clients received de-identified numbers in the database along with a harm reduction card that granted them access to services across all of Ukraine.

> *"Those who came from one region to another, with the harm reduction card can receive services at any HIV prevention point. They can find out about prevention centers through the Internet … And they could [also] contact us directly"* (Poltava, proximal destination).

According to other participants, however, reporting to the SyRex database was not consistent, likely explaining the aberrant results observed in Lviv Oblast. For other participants, reporting to the SyRex database stalled amid the conflict due to the limited capacity of harm reduction organizations.

> *There was no place to document; we didn't even have a place to print the documents out [like we did before the war] … We just did it all*

**FIGURE 2**
The aggregate quantity of unique clients over time (mm/dd/yyyy) who accessed at least one preventive service at sites across Ukraine. The arrow and shaded blue box denote the start date of the Russian invasion (24 February 2022).

> *in a notebook because it was faster* (Obukhiv, Kyiv Oblast, frontline).

When conflict receded in these regions, harm reduction organizations resumed reporting despite these delays.

## Discussion

The Russian invasion of Ukraine poses a major, though not unprecedented, threat to Ukraine's capacity to continue its response to the HIV epidemic (22). As HIV has become a global pandemic, with many regional HIV epidemics being concentrated in PWID, it is critical to understand the Ukrainian response, which is the first of its type. Before the 2022 invasion, prior events, like the Russian invasion in 2014 and the COVID-19 pandemic, also disrupted HIV services and created learning opportunities (12, 23–27). The COVID-19 pandemic, for example, led to increased psychological distress and heightened drug use among people with HIV (28). During the pandemic, harm reduction services were disrupted in similar ways as those identified during the 2022 Russian invasion (as described in this study), but they were much less pronounced, with most services rebounding after a slight decrease after the

initial COVID wave (29). Similarly, the 2014 Russian invasion caused major healthcare disruptions in the occupied areas of Ukraine, likely affecting harm reduction as well (30).

Prior studies have identified similar disruptions to HIV treatment and prevention in Ukraine during the 2022 invasion, though none have focused specifically on harm reduction services to our knowledge. OAMT, a key HIV prevention strategy, has been significantly disrupted, with limited medication supply and rigid guidelines for treating patients that have exacerbated these disruptions (12, 15, 31). As with the healthcare system in Ukraine, access to antiretroviral therapies for treating patients with HIV has also been hindered amid the war (32). Studies on the effects of the war on harm reduction and/or SSPs, however, have been limited. This study therefore offers unique and meaningful insights into other HIV prevention strategies, providing a holistic account of the dynamics of SSPs in Ukraine during the war. Further, it disentangles organizational responses to the war based on context and proximity to actual conflict.

Our findings underline that it is highly important for harm reduction organizations to sufficiently insulate themselves from future disruptor events to ensure continued scale-up of SSPs. Disruption to SSP programs can be directly associated with increased transmission of HIV, making it crucial to continue

FIGURE 3

The quantity of unique clients over time (mm/dd/yyyy) who accessed at least one preventive service in temporarily Russian-controlled regions (Chernihiv and Kherson Oblasts). The arrow and shaded blue box denote the start date of the Russian invasion (24 February 2022).
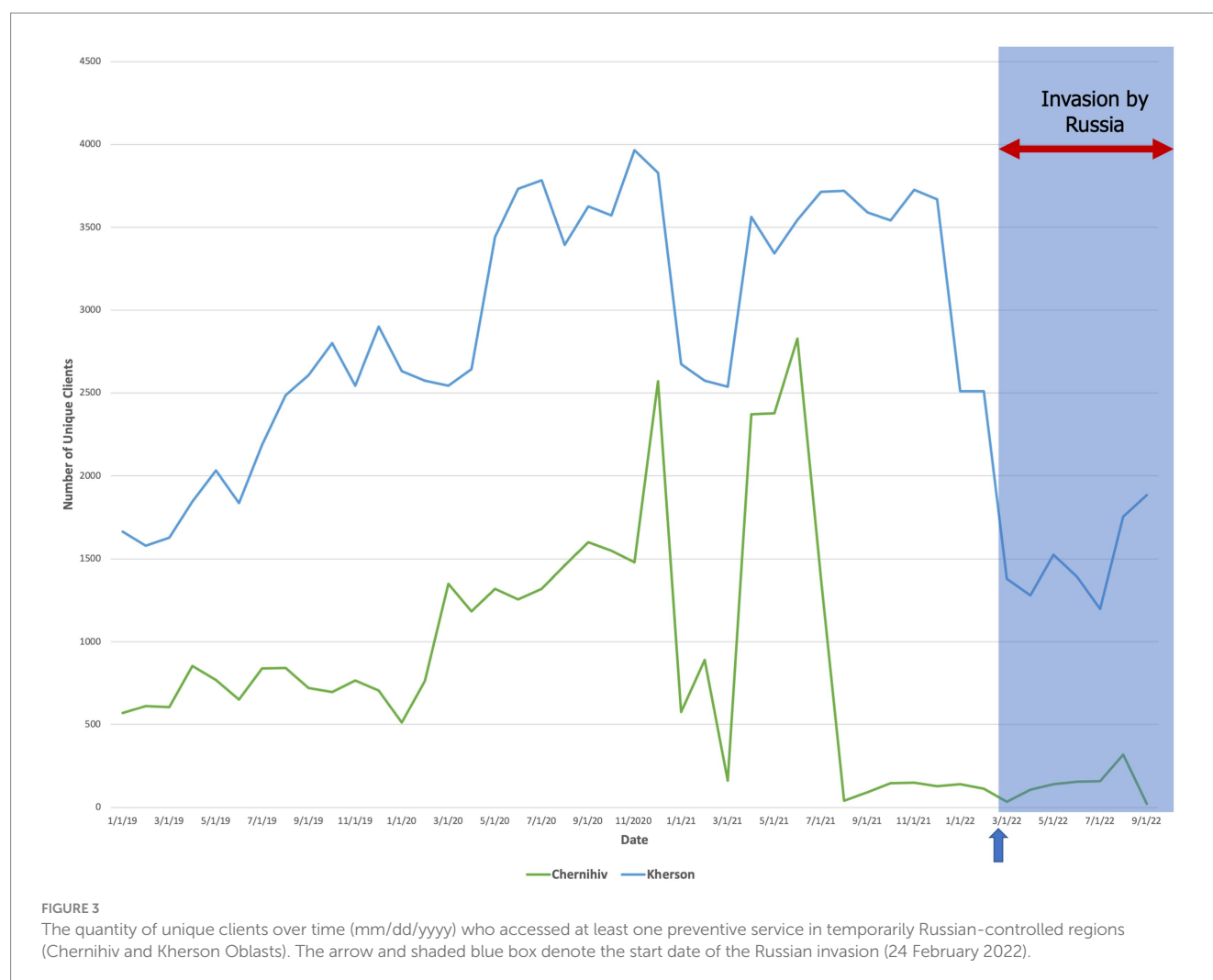
service delivery (33). To date, Ukrainian harm reduction organizations have been largely successful amid these efforts when accounting for the major disruptions the country encountered with the 2014 Russian invasion of Ukraine and the COVID-19 pandemic (15). During the pandemic, for example, harm reduction organizations transitioned SSPs to mobile delivery and client outreach to telecommunications, enabling them to continue scaling up SSPs despite the risks posed by COVID-19 (29). Still, the challenges faced by harm reduction organizations with managing the higher demand and lower supply of SSP during the 2022 Russian invasion, as described in the results, demonstrates the importance of refining existing methods and implementing new ones to ensure that harm reduction organizations can continue scale-up of SSPs despite the war.

One successful strategy that enabled scale-up of OAMT for HIV prevention during the COVID-19 pandemic (15) and again in the early stages of the war (27) was an effective implementation strategy that applied NIATx (The Network for the Improvement of Addiction Treatment) (34), an evidence-informed collaborative learning strategy with a bundle of implementation tools that can be used to scale-up services. In the same vein, the development of collaborative methods for tracking distribution and other metrics

through databases, like the GFATM-funded SyrEx, marks an important innovation to SSP evaluation in Ukraine which can be further leveraged to lower the likelihood of disruptions to scale-up. SyrEx and other databases enable harm reduction organizations to more effectively account for the services that clients require most, which can help guide efficient scale-up of SSPs while accounting for their needs (12). Furthermore, as participants reported in this study, the de-identified client tracking system has helped to improve efficient linkage of clients from one organization to another across the country, which was reported as an innovation for transferring OAMT patients to other regions (12), especially as millions were displaced (13).

SyrEx databases and other methods of data collaboration are therefore crucial for ensuring rapid scale-up during and after disruptor events. First, as proposed by Altice et al. (12) and our study participants, SyrEx can be used in the short term to coordinate more efficient transfers of clients from one harm reduction organization to another amid the high rates of displacement. For example, SSPs can more effectively gauge the needs of new clients by viewing their prior utilization of services in the database. SyrEx can also be leveraged to improve distribution of SIP and funding to harm reduction organizations on an ongoing

**FIGURE 4**
The quantity of unique clients over time (mm/dd/yyyy) who accessed at least one preventive service in frontline regions (Chernihiv and Kherson Oblasts). The arrow and shaded blue box denote the start date of the Russian invasion (24 February 2022).
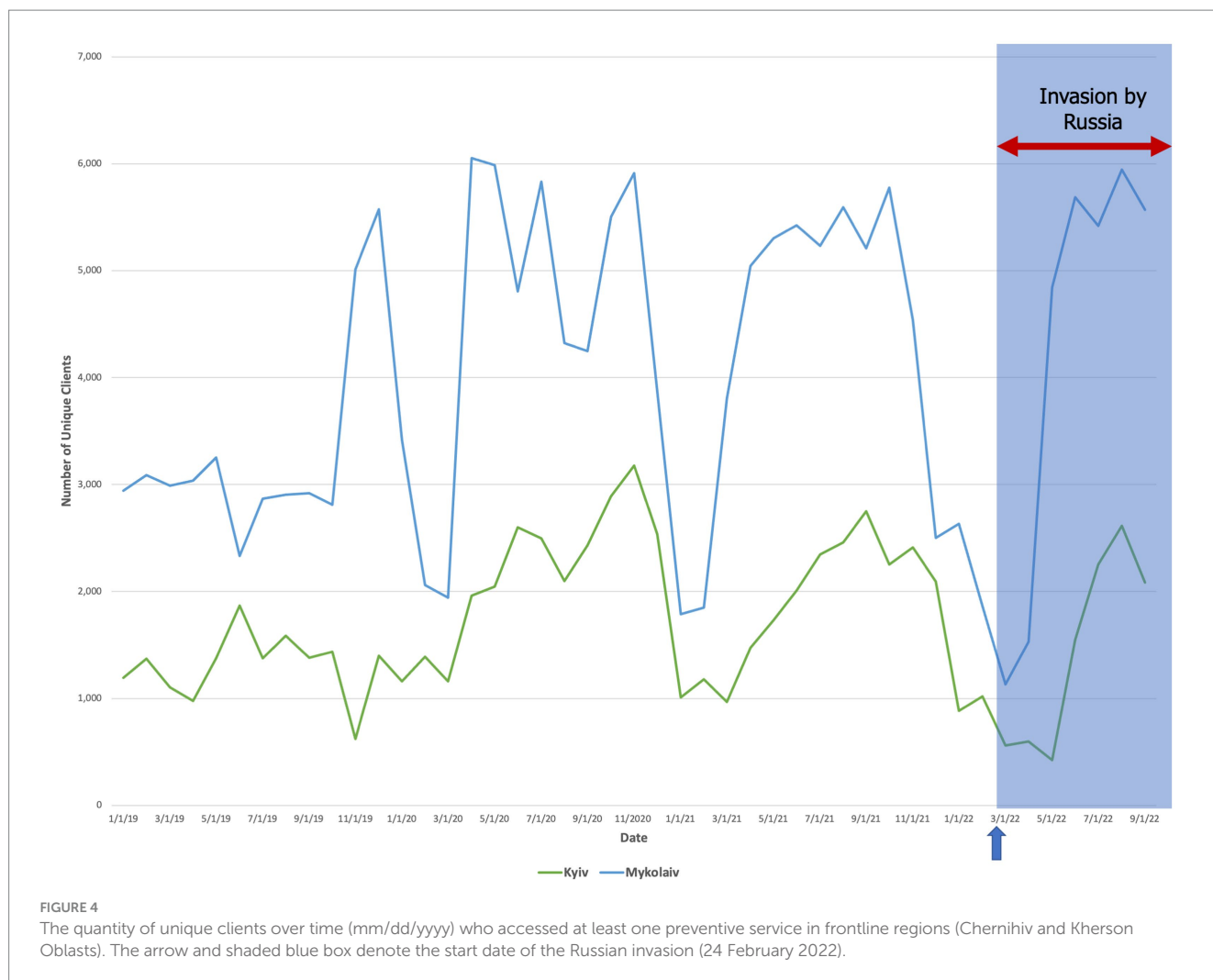
basis. Particularly during the present crisis, when organizations in Russian-controlled and frontline regions have reported inadequate supplies and funding support while organizations outside these regions had surplus access to supplies and funds, the use of quantitative data to adjust distribution, including time-sensitive transfers to other regions, could be crucial. Furthermore, harm reduction organizations should strive to consistently adhere to data reporting, particularly during periods of crisis, so that allocations and client transfers can be uninterrupted.

Non-governmental organizations (NGOs) that provide all of the harm reduction activities in the country have substantially contributed to cost-effective reductions in transmission of HIV and HCV (35). To sustain these gains, NGOs will need to work in concert with each other across the diverse regions of Ukraine to maintain prevention services to control potentially volatile HIV and HCV outbreaks during the war.

The lessons learned from Ukraine have important applications to other settings, especially where HIV and drug use epidemics are intertwined. First, the shift from opioids to stimulants and other non-opioids based on changes in drug supply, requires that SSPs enhance their services during conflict as OAMT has a limited role. Second, the types of settings that are

at risk for such conflicts outside Ukraine are especially tenuous. For example, Russia has already annexed parts of Moldova and Georgia, both with inter-related HIV and opioid epidemics. Therefore, it is crucial for such settings to create preparedness plans for addressing future conflicts (36). Such conflicts extend elsewhere to border disputes between Armenia and Azerbaijan where Russia exerts considerable influence (37). Beyond Eastern Europe and Central Asia, disruptor events like natural disasters, refugee crises, and pandemics could also cause disruptions to SSP service delivery. The COVID-19 pandemic caused major disruptions to SSPs and other harm reduction programs in the U.S. and in most other countries (38). For all countries with SSPs, therefore, it is important that harm reduction staff observe the lessons learned from Ukraine. Some likely steps would be to stock markedly higher levels of sterile injection equipment and to facilitate a smoother transition to large distribution of SIP while concurrently promoting secondary distribution practices where some PWID distribute to their social and injection networks. As suggested in the case of Ukraine, facilitation of increased collaboration and streamlining of client and related data could also have a significant impact on reducing the likelihood of SSP interruption (12).

**FIGURE 5**
The quantity of unique clients over time (mm/dd/yyyy) who accessed at least one preventive service in destination regions (Polatava Oblast, proximal; Lviv and Ivano-Frankivsk Oblasts, distal). The arrow and shaded blue box denote the start date of the Russian invasion (24 February 2022).
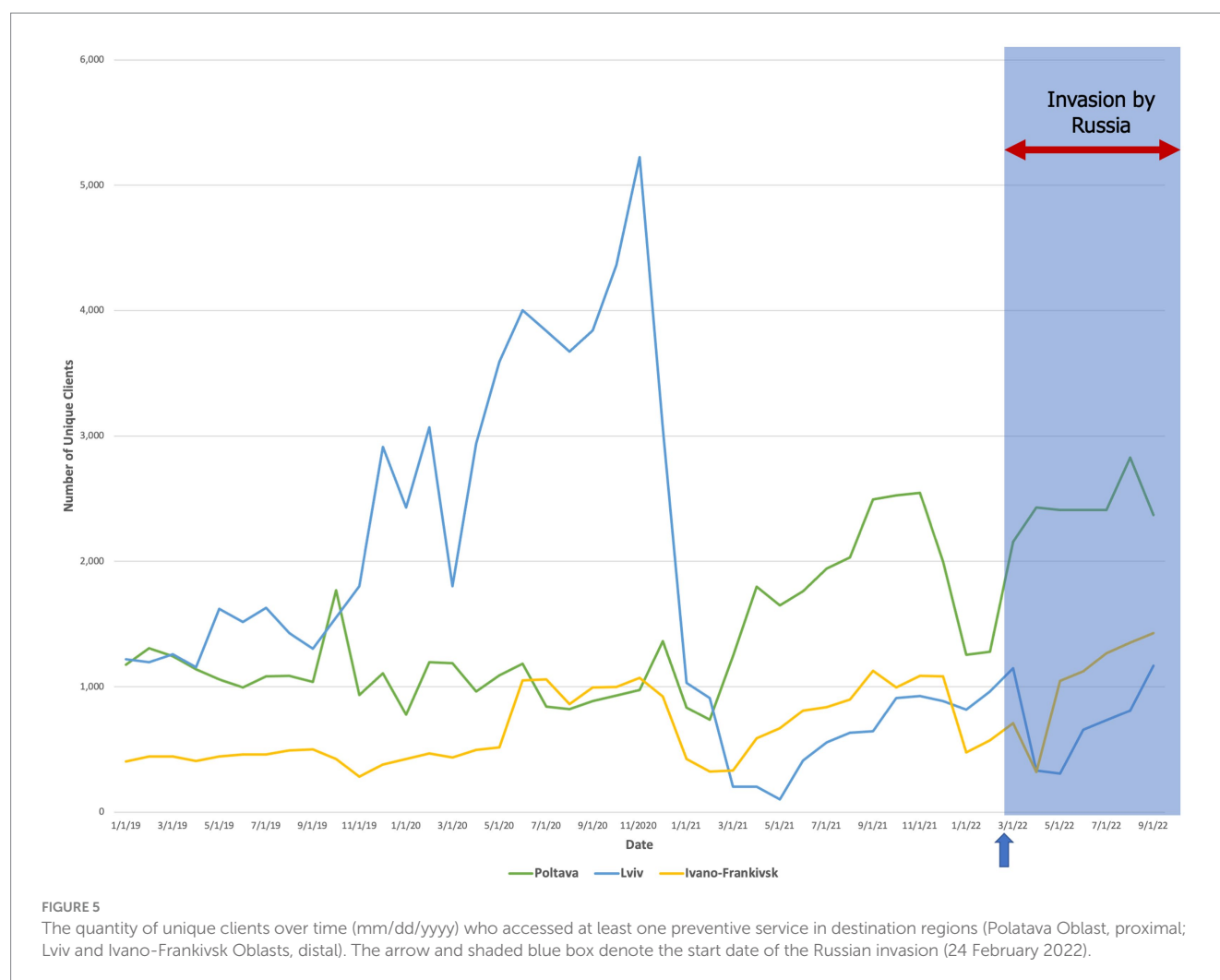
## Limitations

Though this study attempts to summarize the response of harm reduction organizations to barriers during the Russian invasion, it may not provide the full picture of the situation in Ukraine. Rather, it is based on the limited, available quantitative data and in-depth interviews that were performed with purposively selected participants across all regions of interest. Of note, this study does not include data from the Donetsk, Luhansk, or Crimea regions. This was due largely to logistical constraints, as it is very difficult to establish contact with SSPs and/or clients in these areas, which have been under Russian occupation since 2014. Moreover, this study was more focused on the specific response to the 2022 Russian invasion rather than the 2014 invasion.

## Conclusion

Maintenance and scale-up of SSPs in Ukraine is critical to preventing the spread of HIV and HCV for PWID. These programs not only distribute sterile SIP but also support and navigate clients to other services like OAMT that are crucial for

overdose prevention and primary and secondary HIV prevention. Findings here demonstrate that the war has led to pressing and disparate needs across three different zones within Ukraine—Russian-controlled, frontline, and destination. A targeted response should be tailored to each of these prototypical regions with an effective implementation strategy to ensure service continuity. Throughout the country, a national response that adheres to the supply and demand needs of SSPs for each harm reduction organization is critical to sustaining scale-up of SSPs despite the Russian invasion. Mobilization of existing resources like the SyrEx database can be particularly helpful for ensuring an improved response and recovery in the SSP space. These lessons from Ukraine should be applied across other countries that are similarly encountering concurrent HIV and drug injection epidemics.

## Data availability statement

The datasets presented in this study can be found in an online repository. The repository can be accessed at the following link: https://doi.org/10.17605/OSF.IO/BF4SK.

## Ethics statement

The studies involving humans were approved by Yale University and the Ukrainian Institute of Public Health Policy. The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because due to the low-risk nature of the study and the ongoing conflict in Ukraine, both IRBs endorsed collection of verbal consent from participants.

## Author contributions

BN: writing-original draft, conceptualization, methodology, investigation, visualization, and formal analysis DB: conceptualization, methodology, investigation, visualization, writing-review and editing, and formal analysis IP: conceptualization, validation, and resources RI: validation and methodology ZI: validation, resources, and conceptualization. FA: supervision, conceptualization, and validation. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The handling editor JR declared a shared affiliation with the author(s) BN, DB, RI, and FA at the time of review.

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## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1229057/full#supplementary-material

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# Understanding and learning from rural drug service adaptations to opioid substitution therapy during the COVID-19 pandemic: the What C-OST? study

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**Introduction:** In April 2020, in response to government COVID-19 advice, changes were made to the way English drug services operated. Methadone and buprenorphine were typically dispensed in 1- to 2-week supplies, and key working was conducted by phone/online. Previous studies have examined the impact of these changes on people from urban settings. This study adds the experiences and perspectives of people receiving care from drug services in rural areas and makes suggestions for future emergency planning.

**Methods:** Telephone semi-structured interviews were conducted with 15 people receiving care in Somerset, Wiltshire, and Suffolk, rural counties in England. Reflexive thematic analysis was used.

**Results:** Three overarching themes were found. *"Challenges of rural lockdown"* (theme 1) describes how rural community challenges, especially reduced or no rural public transport, were experienced. This hampered some OST collections, with consequential drug use. It also impeded connections to loved ones, worsening isolation. For participants who were struggling pre-pandemic, the intersection between this and their experience of revised drug service operations is embodied in *"Amplification of Social Disconnection: Cut off and unheard"* (theme 2). They felt a lack of support, particularly from remote provision key working. Participants who had supportive relationships and time in the pandemic occupied in ways they found meaningful, and others who struggled with anxiety or depression, found pandemic changes *"Fits better with my life"* (theme 3). They experienced more freedom for other things, gained support by other means, such as family, or felt more comfortable with remote engagement. A cross-cutting sub-theme *"Understandable Interruptions"* showed acceptance of pandemic disruptions.

**Conclusion:** National guidance and organizational policy impacted participants in different ways. Those who had supportive relationships and occupied time were better able to make positive use of newfound freedoms and engage with community-level support. In contrast, those who had less stability, including mental health struggles and social isolation, felt cut off and unheard, particularly

from key workers. Reduced rural transport was a significant community-level issue, which impeded OST collection and social support. We suggest emergency response plans be created for individuals taking account of their pre-existing personal situations.

# 1 Introduction

Increasing drug-related deaths in the United Kingdom (UK) are a public health crisis (1, 2). There is a network of drug treatment services across urban, rural, and small-town locations in the UK. Prescribing is undertaken by doctors, nurses, or pharmacists, with psychosocial support and case management provided by staff commonly referred to as "key workers" or "recovery workers". Opioid substitution treatment (OST), such as methadone and buprenorphine, is prescribed to reduce opioid-related deaths and blood-borne viruses and support recovery from substance use (3). Recovery is defined as "*a process of change through which people improve their health and wellness, live self-directed lives, and strive to reach their full potential*" (3). Dispensing of OST is predominantly carried out by local community (retail) pharmacies. Compared to urban drug treatment services, rural drug treatment services are typically split over several locations across the area they serve, with fewer staff, who may have to travel between working locations, with the more widespread use of outreach. Rural pharmacies are typically smaller than urban ones, with less evening and weekend coverage. There are often challenges recruiting or retaining health and care staff in rural areas, which may have been impacted during the pandemic. Before the COVID-19 pandemic, national prescribing guidance meant many people received OST daily, sometimes consuming under the supervision of a community pharmacist, or in take-home installments of a maximum 1-week supply (4).

As a result of the public health measures introduced in the UK during the COVID-19 pandemic, there were rapid changes to drug treatment service operations. These were introduced because people who use opioid drugs were expected to be at increased risk of COVID-19 transmission and poorer health outcomes due to multi-morbidity (5, 6). Changes were designed to overcome potential barriers to treatment, reduce footfall in pharmacies and drug treatment services, and facilitate self-isolation. Changes included switching from face-to-face prescribing appointments and key working to telephone appointments, conducting of psychosocial groups online (e.g., via Zoom or MS Teams), and moving many people away from daily supervised OST consumption, instead providing take-home doses that covered longer time periods (7). Some services also switched people from methadone to buprenorphine as a risk reduction strategy and increased the speed with which patients were prescribed OST (8). Similar changes were implemented internationally (9).

UK studies conducted in urban areas (10, 11) or mixed urban and rural areas (personal communication) (8) during the

pandemic suggest less frequent OST collection and relaxation of requirements for supervised consumption in pharmacies were generally viewed favorably by people in receipt of OST. Some experienced difficulties with managing large quantities of take-home OST or being pressured to sell or pass on their OST (8, 10). Remote prescribing and key working appointments were seen as convenient, but some found them less beneficial and impersonal, with a negative impact on well-being (8, 10, 11). The lack of in-person socializing brought about by online support groups is noted (10), while other studies (8, 11) report barriers to service access with subsequent loss of connectedness and isolation.

However, little is known about how people who use drug treatment services based in rural areas were affected by changes in pandemic service provision. Research is often focused on urban areas, even though 9.7 million people in England (17.1% population) live in rural areas. It is important to understand their experiences to inform future provision. In the US, the lack of mobile phone coverage in rural areas was a particular barrier to telemedicine (12). Further work from the US notes that rural areas can be subject to regional neglect and issues stemming from geographical isolation such as lower broadband coverage (13). Such regional neglect is also highlighted in England, in a 2022 Parliamentary Inquiry into rural health and care (14). It notes a lack of understanding of the health and wellbeing of people who live in rural England. It identifies healthcare inequities between rural and urban areas, describing poorer healthcare and worse health outcomes in rural areas, compounded by hidden deprivation and poor transport. Before the COVID-19 pandemic, rural transportation provision in England was already in decline (15). During the COVID-19 lockdowns, public transport was restricted further, and timings of services orientated around the working day or stopped altogether. The Parliamentary Inquiry (14) recommends delivering health services suited to the specific needs of rural communities. To do this, we need to first understand what those needs are. Kesten et al. (10) observed that public health measures implemented during the COVID-19 pandemic intersected with existing issues of poverty and isolation in the city of Bristol. We designed this sister study to Kesten's to explore whether people in rural areas had similar or different experiences to the urban studies already reported (8, 10, 11). Our study aimed to understand how changes made to the delivery of drug treatment services as a result of the pandemic response impacted on people who live in rural areas of England and to consider what we can learn for future pandemics or other emergency responses. This will allow approaches tailored to their needs to be developed.

# 2 Materials and methods

What C-OST? was a qualitative, cross-sectional, semi-structured telephone interview study carried out between October 2020 and April 2021.

## 2.1 Setting

Participants were recruited via seven English drug treatment services, in the counties of Wiltshire (South West), Somerset (South West), and Suffolk (South East). These counties cover large rural geographical areas. Recruitment was undertaken from services based in rural towns, as defined by the Office of National Statistics land use classifications. The services covered populations living in small towns, villages, and other rural areas. Services that served predominantly urban areas, as defined by the Office of National Statistics (Swindon in Wiltshire and Ipswich in Suffolk), were excluded. All services included in the study were part of one national third-sector organization that provides drug and alcohol services in these counties.

Data collection commenced in October 2020, shortly before a second national lockdown. The *"Everyone In"* scheme, launched in March 2020, gave funding to local authorities to provide rapid housing for homeless people in commercial hotels and hostels. This program became the Next Steps program in July 2020 with the addition of the Protect Program and Protect Plus Program for areas that needed additional support during lockdown restrictions in the winter. For the purpose of this study, we shall refer to accommodation provided to homeless participants as part of the COVID-19 response as "COVID-19 emergency accommodation". Community pharmacies remained open during the pandemic, enabling people to continue to walk in without an appointment to seek advice, collect medication, or purchase items. They operated with staff and the public wearing masks, Perspex screens, and limits on the number of people entering the pharmacy at a given time. Some operated reduced opening hours, and they were permitted to close for staff breaks. Primary care (general practice) continued to operate, using a pre-booked telephone triage system. Drug treatment services included in this study had previously (pre-pandemic) operated with pre-booked face-to-face key worker and prescriber appointments, and in-person psychosocial support, which included group work. At the start of the pandemic, key worker appointments were switched to telephone, with group work initially paused and then introduced via online platforms. Prescribing reviews for people already on an OST prescription were switched to telephone. People prescribed OST for the first time, or the first time in that treatment episode, continued to be seen face to face with social distancing, masks, and other hygiene measures such as hand sanitizer. On the instruction of Public Health England (7) (now known as the UK Health Security Agency and Office for Health Improvement and Disparities), following risk assessment, most clients received 14-day supplies of OST from their pharmacy from April 2020. This was changed to 7-day supplies later in the pandemic. Pre-pandemic, a greater proportion of clients would have been on daily supervised consumption. No national data are published on supervised consumption levels, but a personal communication with one national provider advised that just over half of their OST clients were on supervised consumption pre-pandemic, and this figure is now around a quarter (2023), having been as low as 14% in the early pandemic phase.

## 2.2 Patient and public involvement

Four people with lived experience of drug use, drug treatment services, and OST gave feedback and comments on the study design and recruitment methods by telephone and online discussions with JS. In response to their comments, minor revisions to the topic guide were made to improve the clarity of the questions. They advised on an acceptable number of times to attempt to contact potential participants. Discussion with two drug treatment service managers confirmed that they considered the proposed methods (see 2.4) to be appropriate and realistic in the pandemic environment. Approval of the protocol was obtained from the management team at headquarters.

## 2.3 Ethics

Ethics approval for the study was obtained from the University of Bath School for Health research ethics committee (Reference: EP 19/20 061).

## 2.4 Recruitment and sampling

Drug service staff were gatekeepers to participants and supported recruitment. They were asked to identify opioid clients on their caseload who met the study inclusion criteria and give information about the study to them at their next telephone appointment. In the UK, the predominant illicit opioid used is heroin. Inclusion criteria were (i) pre-pandemic experience of drug service provision including OST from a rural service and (ii) 18 years or over. Ongoing feedback to gatekeepers attempted to encourage recruitment diversity. Those who expressed an interest in taking part and agreed to have their first name or nickname and telephone contact details shared with the researcher were then contacted by telephone by either HF or JS to arrange a convenient time. Those who agreed were sent a study information sheet (by post, or a link in a text or email). If the person was not contactable, HF/JS tried a maximum of four further times before their details were removed from the recruitment database. If the person declined to interview, their details were removed immediately.

## 2.5 Procedure

Interviews were conducted by JS and HF. As JS is a clinician at one of the study sites, HF engaged with and conducted all interviews with participants recruited from that service. Interviews were carried out by telephone because of the COVID-19 restrictions. When participants were called to be interviewed, the study was explained to them again, and the researcher made sure

that they had seen the participant information sheet. Participants then verbally consented to participation and recording, which was done using a digital Dictaphone. The interviewer checked that the participant was somewhere where they were happy and safe to talk before commencing. At the end of the interview, the researcher debriefed the participants, and they were sent a £10 shopping voucher as an acknowledgment of their time given. Gift-giving audit processes did not permit the sending of cash without recording full names and contact details.

## 2.6 Interview topic guide

A semi-structured topic guide was developed to explore the impact of the pandemic on the individual and their drug use, on their experiences of drug treatment and service engagement, and take-home OST. It was based on the topic guide used for the LUCID-B study (10), which was developed by JK, LH, HF, JS, and other LUCID-B team members. At the start of the interview, participants were told *"We are interested to find out how the COVID-19 pandemic changes have affected people who use drug services who live in rural areas. This information will be used to help us understand how the pandemic has impacted on people like you and help us identify suggestions on ways services should be provided during and after the pandemic"* to preface the purpose of the study. They were also asked *"Would you describe your living location as countryside, village or town?"* to aid the use of appropriate prompts and support interpretation.

The topic guide and data interpretation were also informed by the socio-ecological model (16). This formed the theoretical framework for the study by using questions to explore the impact of government COVID-19 policy restrictions and Public Health England policy and resulting organizational service delivery changes on the individual and their interpersonal relationships/social support.

## 2.7 Data analysis and epistemology

Interview recordings were transcribed verbatim by professional transcribers and checked and anonymized by the interviewers. Reflexive thematic analysis (RTA) (17) was chosen because of its theoretical flexibility and was carried out by JS and JM who adopted a critical realism stance. There is one reality but that this is not independent of the researcher's perspective and their expertise and biases (18). As JS is a clinician and an academic whose research focuses on drug treatment and pharmacy services, she brought this knowledge and awareness to the research. She conceived the research idea with the knowledge that rural drug services and people who live in rural areas may have different experiences of drug services to those who live in inner city areas and that their experiences are often missing from the research literature. JS's practice experience of the service delivery model experienced by study participants informed analysis. JM is an academic and clinical psychologist whose research interests lie in the impact of loneliness and social isolation. JM also brought expertise in the method of RTA. Their joint expertise brought topic-specific

and method-specific expertise to the coding and analysis. NVivo version 12 was used to manage data analysis. Data were coded inductively and framed around aspects of drug service provision, e.g., OST prescribing, dispensing, key working, and psychosocial support. JS and JM met frequently to discuss and refine codes, reflecting on the aim of the research, which led to some joint reorganization and renaming of codes. Once coding was complete, JM and JS met several times during the iterative process of code interpretation and theme building to reach a consensus. During theme building, we explored the impact of changes at different levels of the socio-ecological model on the individual and how, in turn, these changes altered their interpersonal and service provider interactions and relationships.

# 3 Results

## 3.1 Participants

Thirty-three people consented to contact, and 15 (eight women and seven men) completed an interview between October 2020 and April 2021. The remainder were mostly uncontactable after five attempts, or declined, for example, because they had changed their mind. The ages ranged from 31 to 56 years, with an average of 43 years. Table 1 summarizes demographic information about our study participants.

## 3.2 Findings

Some participants had previously experienced a degree of social isolation before the pandemic due to the nature of their pre-existing difficulties with substance use. How participants experienced the changes in rural drug service provision was complicated by this pre-existing and/or current social isolation and influenced by their current relationship with substances. Three overarching themes were identified that depict experiences that were common across participants (as in theme 1) and varied among participants (as in themes 2 and 3). All participants had experienced being locked down in a rural area and pandemic drug services, including prescribing and dispensing of OST in rural areas. Theme 1 *"Challenges of rural lockdown"* encapsulates the difficulties experienced around this. For participants who were struggling with their recovery and treatment before the pandemic, the intersection between their experience of change in drug service operations and participants' pre-existing struggles resulted in an amplification of the latter, as described in Theme 2: *"Amplification of Social Disconnection: Cut off and unheard"*. For participants who had developed what might be described as more significant recovery capital [a term defined as *"the breadth and depth of internal and external resources that can be drawn upon to initiate and sustain recovery"* (19)] or who expressed less need for in-person support, the intersection was perceived to have a positive effect and is described in Theme 3: *"Fits better with my life"*. A cross-cutting sub-theme *"Understandable Interruptions"* ran through each of the overarching themes. Figure 1 conceptualizes the findings of this study.

TABLE 1 Participant demographics.

| Participant code | Gender | Age | Self-defined rurality of place where currently living/sleeping (direct quote) | Accommodation during pandemic | OST medication | Pickup regimen at interview & (pre-pandemic) | Current OST prescribing (script) episode status | Experience of illicit opioids in pandemic? |
|---|---|---|---|---|---|---|---|---|
| SR2 | M | 54 | "a town" | Unstable/sofa surf, now in caravan. | Methadone | Weekly (daily) | On script before start of pandemic | Yes |
| W3 | M | 43 | "Near town center" | Unstable/in car or tent, or with friends since lockdown restrictions eased | Methadone | Daily pickup, was on every 2 weeks (weekly) | On script before start of pandemic. Had restarted recently. | Yes |
| W7 | M | 54 | "Small rural town" | Was homeless then in hostel now back with partner in house | Methadone | Weekly (daily) | On script pre pandemic. Started script again during pandemic. | Yes |
| W8 | F | 34 | "Remote, 3 miles from town" | Living with family | Methadone | Every 2 weeks (daily) | On script before start of pandemic | Yes |
| W12 | F | 31 | "Rural, outside town, no shops" | Housed (refuge) | Methadone | Every 2 weeks (weekly) | On script before start of pandemic | No |
| M15 | M | 38 | "Very rural location" | Unstable/in car | Methadone | Every 2 weeks y (weekly) | On script before start of pandemic | Yes |
| M16 | F | 38 | "Really rural, not much here" | Housed | Methadone | Was every 2 weeks and now weekly (weekly) | On script before start of pandemic | No |
| SF4 | F | 36 | "a small town" | Housed | Buprenorphine | Three times weekly (daily) (declined weekly) | Started current script at start of pandemic | No |
| SF6 | M | 45 | "Tiny little village" | Housed | First methadone/now Buprenorphine | Daily (weekly) | On methadone before start of pandemic. Was on reducing dose, detoxed in pandemic, relapsed, now on buprenorphine. | Yes |
| GB1 | F | 41 | "Small rural town" | Housed | Methadone | Three times week (daily) | On script before start of pandemic | Yes |
| SF5 | F | 51 | "a village" | Housed | Buprenorphine | Every 2 weeks and now weekly (weekly) | On script before start of pandemic | No |
| SF7 | F | 56 | "Very remote…5 miles from nearest shop" | Housed | Methadone | Every 2 weeks (weekly) | On script before start of pandemic | Yes |
| STN2 | M | 47 | "a town" | Was in a tent for 5 months, now housed. | Methadone | Every 2 weeks and now weekly (daily) | On script before start of pandemic | Yes |
| STN7 | M | 44 | "Town center" | Housed | Methadone | Every 2 weeks and now weekly (weekly) | On script before start of pandemic | No |
| STN3 | F | 39 | "Small town" | Housed | Methadone | Every 2 weeks (weekly) | On script before start of pandemic | No |

FIGURE 1
Conceptual model of the study findings.
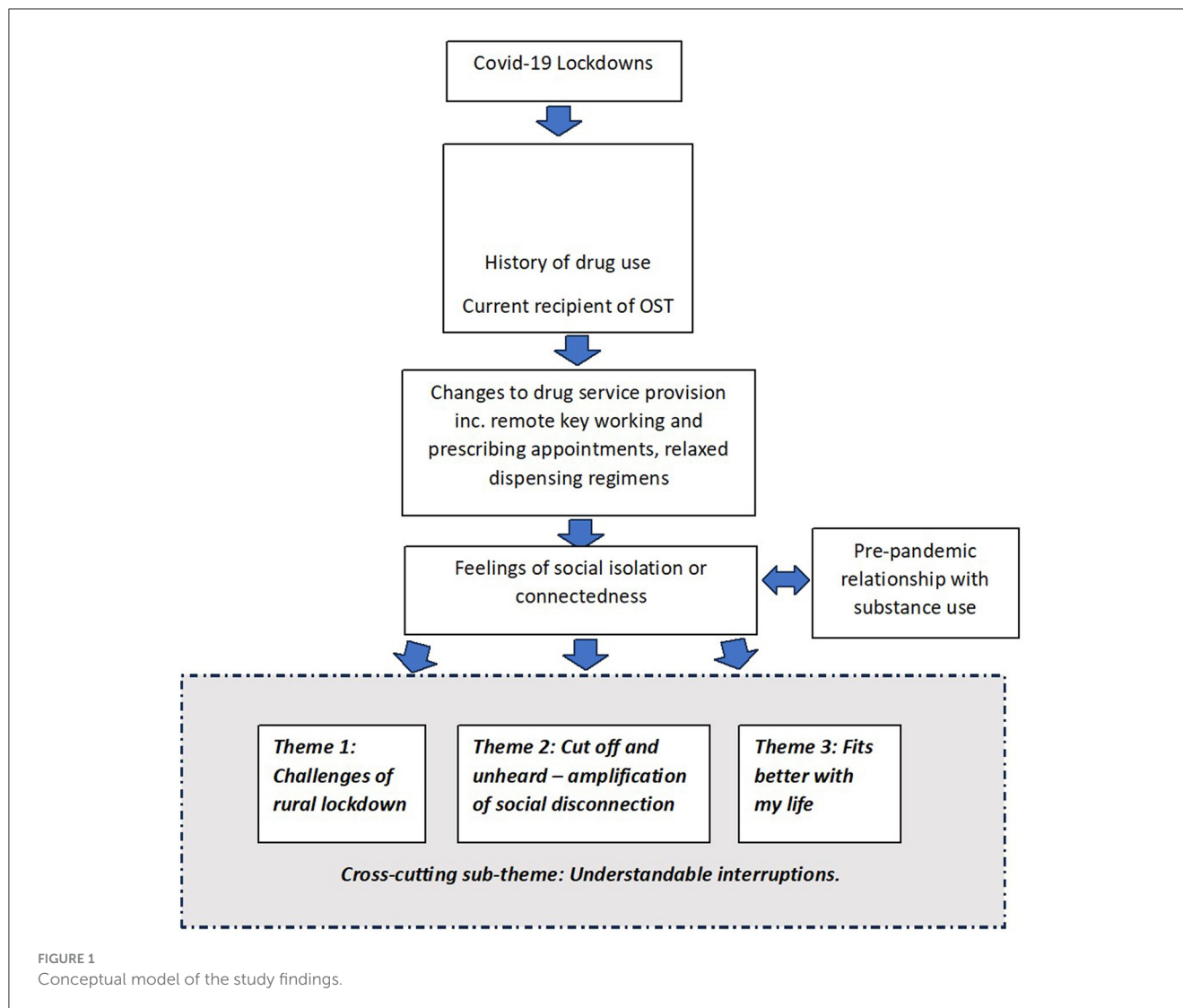
### 3.2.1 Theme 1: challenges of rural lockdown

Participants in this study had experienced significant transportation issues. They largely relied on buses for transportation. Some relied on public transport to facilitate OST collection. They described difficulties caused by infrequent services and how previous short journeys became multi-stage and lengthier or necessitated walking long ways. In some cases, this had contributed to missed collections as GB1 illustrates when describing the twice-a-day bus service from where he had been housed as a result of COVID-19 emergency accommodation to the pharmacy which he had started using previously when homeless:

*"I had to get the bus from where I was put [housed] and the buses only ran certain times of the day, so, and it was an hour and 15 minute journey on the bus to get there [pharmacy] and if I missed that bus, the last bus would be at 5:15pm and there wouldn't be a bus back, so I'd be stuck there…and I thought "no I'm not doing that"… I don't see why I should go to there and spend a night on the streets when I'm housed, that's not happening, so I have missed the odd day". (GB1)*

One person who had no public transport available near their home had to rely on taxis. They reported being able to negotiate a metered fare rather than a fixed price due to regular use, although this remained a significant cost:

*"…it hasn't even got a shop here where I live, it's that small and I don't drive but it is just so lucky like there are taxi services….if the taxi services weren't on, I would have been "nah" [to collecting OST in pandemic] because I had to walk over a mile to get to my script…to walk it is like 40 minutes. But yeah, so I was just kind of lucky that some of the private taxi people were finding it hard in the pandemic, no one wanted to go to taxis, do you know what I mean? so I went out, I used them ….I got to know them and eventually they will just put it on the meter……the first time…they robbed me, [like] I was a tourist or something, I think it was twenty pound the first time and then it went down to twelve pounds". (W12)*

Another participant explained how lack of public transport meant he could not travel for sterile injecting equipment which he

did because he felt ashamed to ask for this at his OST pharmacy. Fear of using public transport in case of catching COVID-19 was mentioned by some. Some participants used pharmacies that had reduced their opening hours, which added to the logistical challenges of travel for OST collection. Others were able to walk to their pharmacy to collect OST so had not experienced public transport barriers in this regard.

Long queues at pharmacies, especially in the early weeks of the pandemic, had meant long waits for OST sometimes stretching to hours. Queues were often attributed to rural pharmacy staff being slow, or to restricted opening hours, rather than overt recognition of the large increase in demand for pharmacy services. Some reported being given priority within the queue because they were a regular client or because they had phoned ahead.

> "They are a bit slow, but I guess they are a small village bloody pharmacy and it is not quite fast pace there …. they are better now I phone them and say look I am coming in, they have it ready for me when I do that". (W12)

However, at times when the pharmacist had been absent (so no medication can be supplied), this had caused stress due to fear that they may not receive their OST.

> "Yeah there's been loads of queues at the pharmacy and stuff and sometimes there hasn't been a chemist there, so I'd have to go back and stuff like that, so yeah it's been quite difficult sometimes". (W7)

Participants largely spoke positively about less frequent pharmacy collections, reducing the stress around pandemic collection circumstances. As shown in Table 1, most participants were experiencing relaxed pickups once every 2 weeks or weekly. Unsupervised, less frequent pharmacy collection was seen as more "normal" (i.e., akin to how other non-OST medications are supplied) and less stigmatizing, giving the flexibility to take medication when preferred, such as at night time, or to split doses for comfort and reassurance. It brought reduced costs and less challenges from rural transport use. W12 illustrates the following:

> "I was able to pick my script up every two weeks, so it really…suited my needs, like, because, if I had to go every single day that would have…it was crazy, trying to get that [pharmacy collection in early days of pandemic], but they understand that I am a mile away [from pharmacy]". (W12)

For some, waiting a long time in queues was made difficult by social anxiety, although less frequent pickups mitigated these challenges to some extent—it was bearable because it only had to be done once a week or every 2 weeks, as W7 shows:

> "Umm I suffer from anxiety and depression and I have bouts where I can't leave the house for months at a time so yeah the less I have to pick up the better really". (W7)

Others described putting up with the queues because of local convenience and the pharmacy staff treating them well. One person expressed concerns about being identified as a person in receipt

of OST to others in his small town who knew him and who were also in the long queues. This centered around the use of indiscreet packaging:

> "All them people I live near [in pharmacy queue]…they [pharmacist] come out with your methadone in a clear bag, so all your neighbors can see it, instead of putting it in a brown bag and being discreet, yeah." (M15)

Appointments to start a prescribing episode or where there had been a break in treatment remained face to face, unchanged from pre-pandemic provision. Most participants had not experienced such an appointment during the pandemic. Telephone prescribing reviews, which were done quarterly, were generally well received and brought relief from the stress of navigating rural travel during the pandemic. The provision of other services remotely, such as key working and group work, was met with more mixed views and experiences, as embodied in themes two and three.

### 3.2.2 Theme 2: "cut off and unheard"—the amplification of social disconnection

There was an intersection between social isolation, drug service operations switching to remote provision, and participants' pre-existing (pre-pandemic) mental health struggles, resulting in the amplification of the latter. Challenges with feeling unsupported, brought about by remote service provision included a sense of disconnection, particularly associated with telephone key working. Feelings of isolation were compounded by loss of social support, including from family and friends. Delays in being able to talk to keyworkers, for example, because of telephone answerphones, were also difficult in times of need. Participants felt unheard or as though they did not know what was happening, resulting in disempowerment. For some, this had led to or escalated substance use linked to worsening mental health. SF7 illustrates this:

> "I live on my own…the total lack of human contact really just being home alone 24/7, it's caused me mental health problems it really has…….Umm it hasn't helped me at all the lack of contact [with drug services], and that, because when, as, my mental health deteriorated, the thought of using drugs was coming in, and when we were going through regular reviews and that, there's also a deterrent that we have, to give a test [urine drug screen], and so there was none of that. So I had nothing to stop me from using if I wanted to, and to be honest when, and I have used on and off through the periods of the lockdown….so it's been really unhelpful to me the lack of service [drugs service contact] and that. Really unhelpful….It was mainly the anxiety levels I just couldn't cope with them, being here on my own… feeling vulnerable and my anxiety just built and built and in the end I just felt I couldn't cope with life and obviously if you go and take some heroin, I know it doesn't make all your problems disappear, but it just puts you in a bubble sort of thing…. I've had depression on and off and for years but I've never had bad anxiety like that it, I just couldn't cope with it". (SF7)

Some participants expressed further frustrations regarding practical barriers to drug service access, such as not being able to

walk into the premises when needed. Getting key worker support was difficult, with emotional consequences that impacted craving and thoughts about substance use compounded by staying home due to the pandemic. STN7 illustrates:

> *"Yeah, because being, sitting there listening to music* [referring to being on-hold on the phone] *is like being in the dentist, it is not what you want happening if you are trying to give up drugs and alcohol, you want somebody to talk to, a face or a voice, just a bit of, you know… I can't think of the word but… just a bit of understanding rather than get wound up by going "these lot* [drug service] *don't care". I have been waiting for hours* [for a call back] *and like I say, before you used to be able to walk straight in the office or phone them straight up and they would say you know, "What's up?" and you could get to talk to somebody…".* (STN7)

Some talked of changes in their allocated key worker that had happened during COVID-19, resulting in not knowing who their key worker was, or not having met them, which amplified feelings of disconnect from the service.

> *"Yeah I don't have a clue who my key worker is at the moment it's forever changing. You can't build up a relationship with someone unfortunately, cause yeah there's always different key workers…..that is a bit of a bummer …..I don't have that sort of knowledge and relationship with them like I've had previously* [pre-pandemic]." (STN3)

Some also talked of how it was easier to avoid engaging with services, as W12 illustrates:

> *"Telephone- I am not going to lie, I have not been very good. Umm she* [key worker] *wants me to do like the group things* [online] *and that, and I haven't really said "no". I said "oh I will try it" and then like I just haven't done it ….she hasn't bothered me again with it".* (W12)

Disconnection was linked to digital poverty, e.g., lack of internet connection or IT skills. Unsurprisingly, given this study methodology, participants did not have difficulties accessing a telephone, but not all had mobile or smartphones. Some described others they knew with no phone access. Some found operating Zoom and Teams calls difficult, especially on phones. When discussing remote access to support, some talked of how impersonal telephone contact was and how much easier it was to open up and build rapport in a face-to-face key working session. GB1 and SF6 illustrate:

> *"Umm I prefer face to face* [appointments with key worker]. *I mean, I've been into body language and psychology my whole life, so I like to be able to look people in the eye when I speak to them, "window to the soul". You know what's going on when you look in the eyes. So when I speak to them* [drug service staff] *on the phone, I can just, all I do is listen to the tone of voice….But yeah I do prefer face to face".* (GB1)
>
> *"Just normal face to face human contact, conversation. I think when someone's doing their recovery, I think it's really important. I think they need that sometimes.*

> *I mean it's great 'cause now we've got phones so they* [key workers] *Facetime and stuff, but it's not quite the same".* (SF6)

### 3.2.3  Theme 3: "fits better with my life"

Participants in this theme experienced helpful engagement with drug services and other sources of support during the pandemic. They found remote service provision suited their needs, gave more freedom, and described benefits to their mental health and well-being from this approach. They described ways to cope during the pandemic to mitigate, at least to some extent, their isolation, stress, and the challenges of rural lockdown described in theme 1. This included stability gained from employment or other daily tasks, examples given included gardening and looking after their house. They found that remote service provision aligned well with their needs and daily routine. For some, it was a preferred time-efficient alternative. People in this theme felt adequate support, some describing a parity between online and pre-pandemic face-to-face service provision. SF4 illustrates:

> *"I think they've* [drug service] *been really good. I mean obviously we haven't been able to meet face to face. I've got a really good key worker, I haven't met him yet, but he's very good at keeping in touch and if I need him at all I can just text him and he'll ring me straight away, he's very good. We had a 40-minute appointment yesterday, so I think it's just been the same sort of thing as he would do it, but just over the phone".* (SF4)

Some expressed a belief that not everyone needed the same level of support as their treatment journey progressed and that remote provision had allowed for this, compared to pre-pandemic service delivery where everyone was felt to be treated the same. STN3 illustrates:

> *"Yeah it would be brilliant if they could* [keep remote service provision after the pandemic]. *Some people do need to go in, and at the start, when I first used the service, I did need that support, but as time goes on, I don't think it should be forced to have that full on support you need to start,* [you should] *be given a bit of space to get your life back".* (STN3)

For others, they felt telephone appointments and online groups fitted better with their mental health, particularly anxiety, which for some had been worsened by pandemic circumstances. They described being able to participate and benefit from groups without leaving their home, something they had been unable to do or struggled to do pre-pandemic. W8 illustrates:

> *"I had probably the most intensive contact with services than ever before, and actually I think it helped in a way, because had I been having to go to meet all these people face to face* [pre-pandemic groups] *and the way I was, with stress and anxiety and everything, I would have found just the thought of travelling and then speaking to somebody face to face, I think I would have found that really, really difficult. So the fact that I could just pick up my phone in my own environment meant that whole process* [was] *a lot easier".* (W8)

The ability to be more anonymous and to have more control over their level of engagement in online groups was welcomed by some. STN7 illustrates:

> "Yeah, it's been really good yeah, we got sent out a workbook, it was an 8 week course with session 8 tomorrow, and you do a breathing exercise, umm, then introduce yourself to the group and talk about how your week has gone, and then you do, like, workbook based exercises and watch little online videos, have a little group chat and then umm, you basically don't have to be on there, you can keep your video off, so they can just hear your voice, so nobody is under pressure to even, you don't even have to say your name you can just put an exclamation mark next to your name you know? So, it has made people do it more, because of that, the fact that you don't have to tell people who you are". (STN7)

Some felt engagement with service providers by phone was enough for them. Engaging with prescribers was important and supportive, but key working and group work were not wanted. STN3 illustrates:

> "I did have the doctors, the prescribers, calling after the few months of them obviously getting a grip on what was going on, the doctors did start calling and they were fantastic. They were talking to us about mental health or talking to me about mental health, if you're having suicidal thoughts, all that sort of thing, but they were really, really supportive. So that was great because obviously it's quite good to talk to a prescriber, you can talk to a case worker but the prescriber is a doctor it just feels like they know a bit more, if you know what I mean".

She then goes on to expand on this point later in the interview:

> "I don't need that side of services much anymore [group work], I just need to make sure [engagement with] the prescriber if I need to talk to someone about my prescription. So I've done everything with the key workers, so there's not really much they could do with me cause I've done all the courses I've done. If I have a bad day I ring the Samaritans [a national crisis helpline]". (STN3)

Some talked of how the pandemic circumstance in general and the cessation of face-to-face attendance at drug services had helped them avoid coming into contact with others who use drugs, which was important to them to support their recovery. W12 explains:

> "They [psychosocial groups] helped me before, they did want me to get into it, I am not going to lie it is not for me.......I find I don't want to hear about other people's horror drug stories and that, I have got enough of my own, do you know what I mean? Sometimes that can affect you, other people's stories, I don't know....like I think I just need to stay away from all of it, and since I have been staying away from all of it and not thinking of all of it, I feel better". (W12)

Some of these participants had also used drugs during the pandemic, but they tended to describe it as a "dabble" meaning it was a one-off or irregular for a short time, often triggered by boredom or fear that supplies would dry up. W8 explains:

> "At the beginning of lockdown I thought, I did have a few dabbles and I didn't need it, obviously, but it was kind of like, well what I'm not doing it nowadays, "'oh my god what if there is suddenly a drought? I'd better do it now even though I'm not involved in that now" so it doesn't matter to me if there is a drought or not, but it was like the toilet roll and the shopping-pasta and rice and flour hysteria, it was like [on] mass, they're all doing it so I'd better do it". (W8)

These participants also experienced rural transport issues and physical isolation. However, they achieved connectedness by making adaptations to their lives, such as joining online activities or self-help groups, such as W8 and SF7 describe:

> "I was wanting to do like a little bit of exercise, for me, but when you're depressed you just don't want to move, and I went onto Reddit and I was talking to people in the depression forum and one of them mentioned that they played Pokémon Go. So you download it onto your phone and then the whole point of the game is that you explore your local community, so you visit cultural sites or historical sites, and they'd actually adapted the game during the pandemic so that you could play it socially distanced and build it into your one bit of exercise a day. And it was through that it got to the point where I was really looking forward to going for my walk, cause otherwise it would have been half an hour endlessly wandering thinking what's the point of this and probably over thinking everything and feeling worse". (W8)
>
> "Yeah I mean I do a lot of NA meetings on Zoom and stuff like that, I do one every day and have done for a few months, a Zoom NA meeting, to try and keep my head in the right place because that is the overall aim, to just reduce off the methadone and not be on anything". (SF7)

She later goes on to say,

> "Yeah I'm doing a basic computer course online, cause I got a laptop not long ago, and thank God I did, cause it's been worth its weight in gold. I mean, I could do the Zoom meetings on my phone but it's not the same sitting there holding your phone as having your laptop open in front of you. So yeah I'm trying to get computer literate and now sorted. I'm a bit more optimistic now coming out of this lockdown, so I've kind of started painting the house and stuff". (SF7)

Some altered living arrangements, or formed support bubbles, building on previously repaired or supportive relationships so tended to not feel so alone.

> "I see my two children [in custody of her parents], [they] haven't been at school through lockdown, so I've been round my mums everyday helping out there so that my mum and dad can still work". (SF4)
>
> "I see my step dad nearly every day and help him out in the garden, things to do now, his garden. Do a bit of work, he's quite active... Yeah and he can see his family". (SR2)

Keeping busy and maintaining normality through continued working were also coping strategies for some. Others such as GB1 kept busy and expressed a preference for being on their own:

> *"Boredom very seldom touches me these days, I can read, I watch movies, I listen to music, I study, I write lyrics - I'm a musician as well, I've got plenty to do".* (GB1)

In addition, a sub-theme of "Understandable Interruptions" ran across the themes. This demonstrates participant acceptance that disruption or interruption to "normal" service provision was inevitable, considering the size and scale of the pandemic. There was a recognition and tolerance of this. The extent to which it was felt services could modify their level of support, as opposed to the way they delivered support, was variable. Some felt that services had done all they could or done their best considering, and some felt that connections made by remote means could have been more frequent or done in a more supportive way. However, others had felt well supported, as described previously. SF7, who had previously completed the group work program face to face, felt she had been offered limited support in the early pandemic:

> *"Umm only I know it was difficult for* [service name] *but I think they really need to find more ways of supporting people. If we get in this situation again, I don't think they can just kind of back off and leave us to do whatever, yeah, it's just not good enough. I know their hands are tied, they couldn't do face to face appointments and things, but I don't know why they couldn't have done some Zoom groups or something like that".* (SF7)

Pharmacies were seen as doing their best considering the demands and restrictions. Two incidents of medication errors were described by separate people, due to wrongly measuring from multidose bottles. Participants largely described managing their medication and taking their doses with no untoward incident.

## 4 Discussion

This study has shown how people who receive care from rural drug services for opioid dependence experienced the support given to them during the COVID-19 pandemic, in response to Public Health England guidance (7), and how it impacted them in the wider context. We found that within their communities, participants experienced significant challenges around rural transport, as transport services were reduced or stopped, which made it more difficult to collect medication, and in one case, sterile injecting equipment. However, difficult journeys were mitigated to some extent by the need to only make them once every 1 or 2 weeks to collect OST. The adaptation of services to conduct prescribing review appointments and key working by phone also reduced the need for such journeys. Relaxation of service engagement requirements was experienced in one of two ways, which intersected with the extent to which the person had wider support or felt isolated. Those who described meaningful occupation of their time and connectedness, as described in theme 3, tended to be better able to make positive use of their newfound freedoms and also better able to engage with community support

beyond the drug service, including online activities and family. We also found some who experienced anxiety were better able to engage with online support compared to in-person groups. In contrast, others felt cut off and unheard, particularly from key workers, as shown in theme 2. They tended to be those who described less stability in their lives at the onset of the pandemic, including mental health struggles and isolation from family. They struggled when trying to make contact with services or with knowing who to contact when they tried. This was contrasted with when it was easier to turn up at the premises and speak to someone face to face. The key worker–client relationship was seen as one of support and had an expectation of being able to discuss sensitive, personal issues, and of being responsive when needed. Some found this more difficult by phone. Infrequent contact from key workers had been experienced by some, across different services. This caused anger and frustration. Less frequent pharmacy OST pickups were welcomed, and pharmacies were mostly seen as having done their best considering the situation.

Many of our findings corroborate with other studies in the UK which have explored how people who use drugs have experienced the changes to drug service provision in urban settings. These studies also found a division in how participants experienced remotely delivered key working and group work (8, 10, 11). Those who had a positive experience acknowledged the benefits of less travel and greater flexibility. These authors also note some struggled to experience positive connections, reported greater isolation, and struggled with technology access. Kesten et al. (10) report how telephone prescribing appointments, less frequent pharmacy collections, and removal of supervised consumption were welcomed and seen as less stigmatizing, as reflected in our findings here. Similar to our study, they found those with poor mental health felt that isolation during lockdowns worsened their mental health. Schofield et al. (8) recruited participants from a mix of urban and rural settings in Scotland, another UK country, although no rurality distinction is made in their findings. We have shown similar experiences among participants who receive care from rural drug services to these previous studies (8, 10, 11) and suggest we found a greater emphasis among our participants on the challenges of rural transport, which as said was already in decline pre-pandemic (15).

Reflecting on international comparisons, Levander et al. (20) and Hoffman et al. (21) studied the impact of relaxed methadone take-home dosing in two rural opioid treatment programs in Oregon, USA. Both studies include findings that reflect those of our first and third themes. Both report greater take-home methadone dosing was welcomed because of the practical challenges and stress of rural travel in the pandemic and because of the greater freedoms that participants experienced allowing them to do other things, such as connect with family. Bolinski et al. (22) explored the experiences of people who use drugs in rural Illinois, USA. They found that some drug use escalated due to boredom and stress from the pandemic, which in turn amplified poor mental health, particularly depression. This reflects the experience we found in theme 2. Thakarar et al. (12) studied how the COVID-19 pandemic impacted on harm reduction services in Maine, USA (a rural state). They found benefits of remote (telehealth) prescribing appointments and outreach services during the pandemic and the provision of remote peer support groups overcame barriers of travel

in rural areas. Their description of models of service delivery in Maine appears very different from those in England, so this may impede direct comparisons. For example, they report one-for-one needle exchange, which is not policy in England (23) and they report experiences of stigma from rural pharmacies, something not reflected in our findings.

Considering what we can learn from this study to inform future emergency response plans, we need to reflect on the approach that was taken in April 2020 across England in response to national advice (7). This advice and the consequent response of services are applied to both urban and rural settings. In future, rural issues could be considered at the national policy and guidance level and at the drug treatment service organization leadership level. The organization from which we recruited developed a risk assessment tool, which considered, among other things, the most recent mental health information, based on the person's last prescribing review or contact. This tool was used to assess risk for relaxed OST collection but not key working engagement. It was applied across the organization. Going forward, our findings suggest this tool could be reviewed, for example, to prioritize key working engagement for those with known current mental health struggles and/or social isolation as our findings showed some experiencing these issues wanted more support. We also suggest that an individualized approach is needed to decide the interventions offered going forward. Accounting for those who are more stable and want less contact and more freedom may be appropriate as our results in theme 3 suggest. Additionally, the tool should consider further local adaptations needed for people who use rural drug treatment services to take into account the difficulties amplified by the lack of transport reflected in Theme 1.

The dispensing of methadone into daily dose-measured bottles was advocated in national pandemic guidance (7) and requested on prescriptions from drug treatment services in our study. Some of our participants reported this had not been followed and had contributed to errors they made in dosing. This was also identified as a factor in a coroner's *Prevention of Future Deaths* report made during the pandemic in relation to a death in one of our study areas (24). We, therefore, want to emphasize to pharmacy staff, the importance of following such guidance and advising people on how to take and store their methadone safely. We recognize to do so when under the extreme work pressures of the early pandemic may have been difficult.

We suggest an online "engagement group" could be co-designed with people who use rural drug services, in readiness for future emergency needs. This engagement group could be specifically deployed to reduce isolation and maintain contact rather than deliver specific psychosocial interventions. Such a group could be a time and staff-efficient way to offer connection to those who would otherwise experience isolation. This could respond to the needs and suggestions identified in theme 2, where participants felt more contact was needed, although it may not overcome the sense of online contact being "not quite the same". One of our participants suggested planning a buddy system bringing together lonely people which could be further explored.

In addition, depending on the nature of the emergency and government restrictions, it is suggested consideration is given to maintain outreach services in rural areas to connect with less

stable clients and to ensure rural needle and syringe provision, e.g., by home delivery, as described by Kesten et al. (10) Bolinki et al. (22) found that such a model in rural Illinois, delivered with PPE and contactless, reached people during the pandemic who had not previously used the service and gave some much needed social support which they could not get elsewhere. Thakarar et al. (12) report collaborative working between organizations that support people who use drugs to facilitate rural harm reduction services. Such joint working during an emergency situation could be explored at the community level in rural areas in England, although the reliance of many on volunteers may be a barrier. We also suggest advanced thought is given to how to support people to access online offerings, both from the perspective of digital poverty and skills, and around their willingness and comfort to engage in this way. This is essential before any online engagement group, or buddy system, as suggested above, could be operationalized. Our findings also suggest more work is needed to understand, develop, and train staff on effective and acceptable remote key working delivery, for example, accounting for non-verbal communication cues in telephone appointments and trying to reduce the variability in remote key working experiences that this study found. We acknowledge we have not studied rural drug treatment service staff perceptions of remote key working or prescribing, which is a gap that needs to be part of future work.

Our findings suggest that although people experienced long pharmacy queues and some difficult journeys, these disruptions were accepted and mitigated by less frequent pickup. Participants in our study welcomed less frequent OST collection which felt more "normal" and less stigmatizing. When asked about consumption of medication at home, most had managed without incident and those reported can be mitigated as described. Consideration needs to be given to allowing greater flexibility in take-home dosing for people who are stable on OST going forward. Lister and Lister (25) note in rural parts of the USA, 28-day take-homes were given to patients deemed "stable" and 14-day take-homes for those deemed "less stable" but able to handle and store take-home doses safely. It is not clear how this was assessed. Those who have managed well on less frequent pickups should only be returned to more frequent dispensing if there is justification for the cost to the public purse and the inconvenience that this brings. When looking for such justification, we must consider the evidence to support the use of supervised consumption of OST, a practice which was started in Scotland in the mid-1990s when drug treatment services had long waiting lists, to reduce diversion. Ecological studies of supervised consumption have found an association with decreased methadone-related deaths (26), and other evidence indicates limited effects on retention, abstinence, mortality, or other adverse events (27–31). Furthermore, methadone diversion, which supervised consumption aims to prevent, may help people manage their drug use, prevent withdrawal, reduce hepatitis C risks, and develop social relationships (32). Analysis suggests that those prescribed methadone in England did not experience a greater number of methadone-related deaths during the first UK lockdown (March to June 2020), but conversely there was a large increase in methadone-related deaths among those not in receipt of prescribed methadone (i.e., taking non-prescribed methadone) (33). These authors found no significant increase

for buprenorphine deaths in either group (prescribed vs. non-prescribed). Data for the subsequent months of the pandemic are yet to be published. Data make no distinction between rural and urban locations or supervised consumption status. A large ecological study is underway to understand mortality outcomes from the removal of supervised consumption during the pandemic (34) which is welcomed to inform future practice.

## 5  Strengths and limitations

This study shines a spotlight on the experiences of people in receipt of OST living in rural areas in the South of England, considering the intersection of individual- and community-level factors with national guidance and organizational policy. Previous study has focused on urban areas. This study echoes the findings of previous studies with added emphasis on the challenges people in rural areas faced, mostly around rural transport and the mitigation of these challenges, e.g., by less frequent OST collections and online groupwork. By showing these similarities, we bring the experience of people in rural areas into consideration of how people who use drugs and drug services experienced the COVID-19 pandemic changes to service provision. This study recruited people from a range of rural settings with over half the sample being women. By nature of the research we were not able to include people who did not have access to a phone, they would have been completely cut off from remote service provision. Their voices are not heard in this study which is a limitation. Considering previous UK studies, there are several similarities in findings, for example, mixed experiences of online service provision, a loss of connectedness with services felt by some and favorable views on lack of supervised dosing, and reduced OST collections (8, 10, 11). Challenges in undertaking research during a pandemic were faced. As experienced researchers in the field, we consider this recruitment to be more challenging than our previous in-person experiences. Online working caused difficulties in gaining visibility of the research team within services and to potential recruits. The pandemic circumstances meant services were under pressure and experiencing greater staff sickness, alongside the very rapid change in service delivery. Reliance on key workers as gatekeepers, most of whom were not known to us, impacted on our slow recruitment rates; it took 6 months to recruit and interview our participants. About half of the people who agreed to be contacted were recruited. Most who were not recruited were not contactable rather than they overtly declined. It was a difficult balance to try to deliver frequent gatekeeper reminders that did not feel like additional pressure, or to repeatedly try to contact potential participants without feeling we were harassing. Participants were recruited from one organization, so the way in which key working was delivered during the pandemic may have differed from that of other organizations although all services operated under national guidance (7). Finally, we must consider that our data were collected over a wider timeframe of the pandemic than the other studies that we draw upon (8, 10, 11) which may mean our participants had adapted to a greater extent to the "new normal" they were experiencing at the time.

## 6  Conclusion

The results from this study in rural settings reflected similar findings to previous studies in urban settings but with greater emphasis on the challenges from changes to public transport due to the pandemic. For people already struggling, the pandemic worsened their isolation and feelings of disconnection and impacted their ability to feel heard, particularly in their interactions with key workers. Those who felt more "on track" benefited from revised ways of engagement and less intrusion from the treatment system into their lives. Those who struggled with face-to-face engagement due to anxiety found it easier to engage with and benefited more from remote service provision. Pharmacy access was acceptable although difficult for some due to limited rural transport. This was mitigated by less frequent OST collections, which were welcomed. Considering future emergency situation response, we suggest involving clients in developing their own response plans and possibly online support models, within the permitted societal emergency response framework.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by University of Bath School for Health Research Ethics Committee (Reference: EP 19/20 061). The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because telephone interviews conducted when COVID pandemic restrictions were in place.

## Author contributions

JS conceived the idea for this study, informed by her work as a pharmacist prescriber in a rural drug and alcohol service, and the Lucid-B study, led by LH, which JS worked on with JK and HF. LH, JK, and HF contributed their experience from LUCID-B. JS and HF undertook the What C-OST? study recruitment and interviews. JS and JM undertook the thematic analysis and led on data interpretation and conceptualization. JM developed the conceptual model of the study findings (Figure 1) and contributed her expertise from the mental health field. All authors contributed to regular study meetings, study design, interview schedule design, data interpretation, and writing of this manuscript equally.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# High perceived stress in patients on opioid agonist therapies during rapid transitional response to the COVID-19 pandemic in Ukraine

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**Background:** The COVID-19 pandemic resulted in marked disruptions in healthcare delivery in Ukraine related to emergency guidance in response to treating opioid use disorder (OUD). Patients with OUD, a group with high levels of comorbid medical and psychiatric disorders, and prescribed opioid agonist therapies (OAT) were rapidly shifted to take-home dosing if they were deemed clinically stable. The impact of these shifts on patient stress and related substance use during the pandemic, however, is unknown.

**Methods:** In early May 2020, 269 randomly selected OAT patients in Ukraine were surveyed to assess their stress level and substance use using the validated Perceived Stress Scale and examined correlates of severe perceived stress.

**Results:** Overall, 195 (72.5%) met criteria for moderate to severe levels of stress, which was independently correlated with having started OAT within the past 12 months (aOR: 1.33; 95%CI: 1.15−1.55), living in a large metropolitan area (aOR: 1.31; 95%CI: 1.18−1.46), having been asked by others to share their medication (aOR: 1.13; 95%CI: 1.02−1.25), and having an increase of over 10 min in transportation time to get to treatment (aOR: 1.16; 95%CI: 1.04−1.29). Twenty seven (10%) patients felt at high risk of relapse, while 24 (8.9%) patients reported purchasing drugs.

**Conclusion:** During a time of great uncertainty soon after emergency guidance to the COVID-19 pandemic, there was extraordinary high levels of perceived stress reported. In response to emergency guidance, OAT patients should be screened for perceived stress and certain subgroups should be targeted for additional psychosocial support.

KEYWORDS

opioid agonist therapies, methadone, buprenorphine, stress, COVID-19, Ukraine

# Introduction

The unprecedented impact to health systems due to the COVID-19 pandemic has introduced new challenges and increased the risk for people with opioid use disorder (OUD), who are particularly vulnerable to stress—a documented psychological effect of the pandemic (1–3). Stress has emerged as one of the main psychological consequences to the COVID-19 pandemic, as

individuals become fearful of COVID-19 infection, socioeconomic consequences, and traumatic stress symptoms, among other stress-induced negative effects (4, 5). In some populations, over half of all individuals have reported the adverse psychological consequences of COVID-19 as moderate to severe (6). For people with OUD, stress has long been associated with more negative treatment outcomes, potentially influencing opioid agonist therapy (OAT) at every step along the opioid treatment cascade by contributing to treatment dropout (7), craving, and substance use relapse or increased use among people with OUD (7–9).

Ukraine is a middle-income country in the Eastern Europe and Central Asian (EECA) region (10), the largest region globally where both new HIV infections and HIV-related mortality continues to rise, fueled primarily by people who inject drugs (PWID)—mostly of opioids (11, 12). Ukraine introduced OAT in 2004, primarily as HIV prevention (13), yet scale-up has been slow, constrained by patient, clinic, and policy factors (14–20). The first case of COVID-19 in Ukraine was diagnosed on March 3, 2020, followed by the first death 15 days later. At the onset of the pandemic, there were 12,837 people receiving OAT in Ukraine, representing only 2.9% of all PWID in Ukraine, an improvement from previous years but still falling well below the minimum 20% coverage level recommended to most efficiently reduce HIV transmission in the country (21). In response to the pandemic, narcologists (addiction treatment specialists) followed guidance from the country's Center for Public Health to identify and transfer a significant number of their stable patients from daily, in-clinic, methadone dosing to 7- and 10-day take-home doses (22).

While reducing program demands on patients in treatment may have reduced COVID-19 transmission by reducing daily in-person interactions between clinicians and patients, narcologists remained concerned about the possible psychological effects of reduced interpersonal contact and oversight with their OAT patients. Psychiatric disorders, especially mood disorders, are particularly prevalent in Ukraine (23). This circumstance is exacerbated by ongoing conflict in the Crimea and Donbas regions (24), political unrest, and economic insecurity. Such disorders are distinctly more prevalent in OAT patients (50–64%) relative to the general population (25). At the same time, these patients experience less access than non-OUD patients to psychiatric treatment (including therapy and medication). This is occurring in a country where access to mental health and psychiatric treatment and services is limited (26) and stigmatized (27). Furthermore, the economic impact of COVID-19 increased isolation due to physical distancing measures, uncertainty about an ongoing pandemic, fear of contracting COVID-19, traumatic stress symptoms as a result of direct or indirect exposure to COVID-19, and a constantly changing social environment, each of which may magnify stress. These factors potentially impact the psychological well-being of patients on OAT (4, 8, 28, 29). In our exploration of the stress status of OAT patients in Ukraine, we seek to understand the effects of the COVID-19 pandemic on the perceived stress among OAT patients by examining their exposure to stress-inducing circumstances and related substance use in response to an evolving pandemic during the initial phases.

## Methods

For this study, we randomly surveyed 269 participants by telephone from May 4–15, 2020 by trained interviewers from the 12 administrative regions of Ukraine that have more than 400 patients on OAT (Kyiv, Vinnytsia, Dnipro, Kryvyi Rig, Donetsk, Zaporizhzhia, Kirovograd, Poltava, Odesa, Sumy, Mykolayiv and Cherkasy) using the Perceived Stress Scale (PSS) along with tailored questions regarding stressors and behaviors related to having OUD and drug use. Twenty OAT patients were randomly selected from each of the participating regions using the SYREX database – a national register of all OAT patients in Ukraine. Subsequently, individuals participating in methadone therapy were selected through a random sampling procedure. Using the EpiTools Sample Size Calculator, a prevalence of 0.2 and precision of 0.05 in the known number of patients on OAT suggested that 246 participants were needed (30). Upon their arrival for methadone treatment, an attending nurse extended an invitation to these patients to partake in the research study. In the event of an affirmative response, patients were directed to a research assistant, where they anonymously underwent the informed consent process and completed the survey. Notably, there were no instances of patient refusal among those solicited for survey participation. Each phone survey took about 15 min. The interview included 3 sections: (1) socio-demographic information (age, gender, education, employment and marital status); (2) the PSS (31), which was translated and back-translated for cultural understanding (32); and (3) behavioral responses during the pandemic. After initially sampling 255 participants, we purposefully sampled an additional 14 patients at random from these sites to ensure enough new patients to OAT (≤12 months), given the known association between stress and recent treatment initiation and to ensure that our sample was representative of OAT patients in Ukraine (8). Data were analyzed utilizing the R statistical software, with the addition of the "plyr," "MASS," and "psy" packages. After initial scoring of the PSS instrument, variables were recoded for analysis as factors in a logistic regression. The primary outcome was moderate to severe perceived stress, defined as having a score > 13. Independent variables were primarily dichotomized. For the change in time to get to the OAT clinic, the variable was dichotomized at the median (10 min more travel time). Multivariable logarithmic regression analysis was conducted to establish the independent correlates of reporting moderate to severe stress levels. Only statistically significant variables ($p \leq 0.05$) were included in the final model. Inclusion of non-significant variables in the final model did not change the final outcomes.

## Ethical considerations

At the beginning of the phone interview, each participant was provided with detailed description of research and provided oral informed consent before the survey began. All study tools and ethical oversight were approved by the Institutional Review Board at the Alliance for Public Health in Kyiv, Ukraine.

## Results

Participant characteristics ($N = 269$) are reported in Table 1. Participants were primarily from highly populated areas, with two thirds of participants living in cities with over one million inhabitants. The mean age was 40 years (sd = 8.8) with an average of 72 (sd = 52.9) months on OAT, with 14% of all participants having initiated OAT

TABLE 1 Participant characteristics (N = 269).

| Variables | N | % |
| --- | --- | --- |
| **Region size** | | |
| >1 million | 178 | 66.2 |
| < 1 million | 91 | 33.8 |
| Mean age, years | 40 | 10* |
| **Sex** | | |
| Male | 191 | 71.0 |
| Female | 78 | 29.0 |
| **Education** | | |
| Secondary or less | 83 | 30.9 |
| Beyond secondary | 186 | 69.1 |
| **Marriage status** | | |
| Married | 126 | 46.8 |
| Not married | 143 | 53.2 |
| **Employment status** | | |
| Employed | 118 | 43.9 |
| Unemployed | 151 | 56.1 |
| **Time on OAT** | | |
| <12 months | 38 | 14.1 |
| ≥12 months | 231 | 85.9 |
| **Increase in time to clinic of over 10min** | | |
| yes | 109 | 40.5 |
| no | 160 | 59.5 |
| **Perceived stress category** | | |
| low stress | 74 | 27.5 |
| moderate to severe stress | 195 | 72.5 |
| **Has been asked to share drugs since the beginning of the COVID-19 pandemic** | | |
| Yes | 86 | 32.0 |
| No | 183 | 68.0 |
| **Perceived risk of relapse relative to before COVID-19** | | |
| Higher | 27 | 10.0 |
| Similar or lower | 242 | 90.0 |
| **Bought drugs since COVID-1** | | |
| Bought drugs | 24 | 8.9 |
| Did not buy drugs | 245 | 91.1 |

OAT, opioid agonist therapy. *Indicates the Inter-Quartile Range.

within the last 12 months. Approximately half of those interviewed were married and over 56% of them were unemployed. These findings are similar to other studies of PWID on OAT (33). The mean PSS score was 16.9 (sd = 6.3), with 27.5% (n = 74) meeting criteria for low-perceived stress, 68.4% (n = 184) for moderate perceived stress, and 4.1% (n = 11) for severe perceived stress.

Participants reported a median increase of 10 (IQR: 0–25) minutes in travel time to their OAT dispensing site due to transportation restrictions imposed by the Ukrainian government during the COVID-19 pandemic, with 40% of them reporting an increase in

travel time of over 10 min. Additionally, approximately one third (n = 86) reported having been asked to share their OAT medication during the COVID-19 quarantine, and 8.9% (n = 24) reported buying drugs during the quarantine, with the large majority of those who reported having bought drugs stating that they were not any more difficult to obtain than the time before the quarantine (n = 17). Despite the changes that emerged during the early COVID-19 restrictions, only 10.0% (n = 27) of all participants reported feeling at a higher risk of relapse due to the pandemic and its ensuing challenges—the large majority felt their risk of relapse remained the same and 24 (8.9%) had purchased drugs while on OAT.

Multiple regression analysis findings are reported in Table 2. Overall, 195 (72.5%) met criteria for moderate to severe perceived stress, which was independently correlated having started OAT within the past 12 months (aOR: 1.33; 95%CI: 1.15–1.55), living in a large metropolitan area (aOR: 1.31; 95%CI: 1.18–1.46), having been asked to share their treatment medication (aOR: 1.16; 95%CI: 1.04–1.29), and having an increase of over 10 min in travel time to get to the OAT clinic for treatment (aOR: 1.13; 95%CI: 1.02–1.25). Being unemployed resulted as a variable in the final, fitted model, but its effect on the outcome was not significant.

## Discussion

Similar to findings of the initial COVID-19 outbreak in China, perceived stress (6) and generalized anxiety disorders (5) were high. The levels of perceived moderate to severe stress among patients with OUD, however, were markedly higher among oud study cohort than reported in the general population. This is especially concerning since a report from the Well Being Trust suggested that economic and employment consequences of COVID-19 could result in markedly higher levels of drug and alcohol use, resulting in markedly elevated levels of "deaths of despair" (34). These negative outcomes are even more likely in a population prone to drug misuse reported elsewhere (35, 36). In this study, the concomitant concern about and actual purchase of drugs was relatively low and similar to reports from OAT patients in Ukraine long before the pandemic (37). In people with OUD, and especially those in treatment in which they must travel regularly (for many, daily travel is required for supervised dosing) to a medical clinic in person to receive their medications, the risk to these individuals for acquiring COVID-19 is heightened. One report from the United States suggests that people with OUD are at over a 10-fold elevated risk for becoming infected with COVID-19 (38), which may contribute markedly to stress levels in OAT patients.

There are several important findings from this study that merit attention, not only for Ukraine, a country with an extraordinary level of OUD, but for other countries that are experiencing a more profound COVID-19 epidemic. In fact, the COVID-19 epidemic was not nearly as severe in Ukraine as in Western Europe and North America at the time of the survey. Findings from the multivariable analysis provide some important insights into who to target for screening for stress and then prioritize them for supplemental psychosocial support. This is especially important given the extraordinarily high proportion of OAT patients reporting moderate to severe perceived stress. The rationale for intervening with OAT patients, especially those who are relatively new to OAT, are vulnerable to relapse to drug or alcohol use and consequently at elevated risk for overdose. In this study, though there

TABLE 2 Independent correlates of having severe perceived stress levels (*N* = 269).

| Variables | uOR | 95% CI | *p* value | aOR | 95% CI | *p* value |
|---|---|---|---|---|---|---|
| Intercept | 1.24 | 0.86, 1.79 | 0.248 | 1.42 | 1.25, 1.62 | <0.001 |
| Large Metro Area (> 1 million) | 1.31 | 1.17, 1.46 | <0.001 | 1.31 | 1.18, 1.46 | <0.001 |
| Age | 1.00 | 0.99, 1.01 | 0.556 | – | – | – |
| Sex (Male) | 1.05 | 0.94, 1.18 | 0.368 | – | – | – |
| New to OAT | 1.35 | 1.12, 1.62 | 0.002 | 1.33 | 1.15, 1.55 | <0.001 |
| Did not complete secondary education | 0.99 | 0.87, 1.11 | 0.876 | – | – | – |
| Not Being Married | 1.07 | 0.96, 1.19 | 0.206 | – | – | – |
| Being Unemployed | 1.11 | 0.99, 1.23 | 0.074 | 1.09 | 0.98, 1.22 | 0.100 |
| Increased time to OAT Clinic (10+ min) | 1.13 | 1.02, 1.26 | 0.021 | 1.13 | 1.02, 1.25 | 0.020 |
| Asked to Share Drugs | 1.15 | 1.02, 1.29 | 0.023 | 1.16 | 1.04, 1.29 | 0.011 |
| High Risk for Relapse Perception | 1.04 | 0.84, 1.27 | 0.737 | – | – | – |
| Has Bought Drugs | 1.00 | 0.82, 1.23 | 0.977 | – | – | – |

uOR, unadjusted Odds Ratio; CI, Confidence Interval; aOR, adjusted Odds Ration; OAT, Opioid Agonist Therapy.

is no matched comparison to drug use in the pre-COVID period, the level of self-reported drug use was not high. Explanations for the low level of drug use may include social desirability bias or that patients were less vulnerable because they were prescribed optimal dosages of methadone. Though the methadone dose was not reported in this survey, a large proportion of patients on OAT in Ukraine receive optimal dosing (33), which may have been sufficient to reduce cravings even in the presence of high perceived stress. Moreover, changes in life circumstances can contribute to stress. For example, most patients in our sample had increased travel time to receive their medications (sometimes daily). Increased travel time of 10 min or more correlated with higher severe stress levels. While other studies have shown that stress and anxiety levels are generally higher in more urban settings (perhaps related to where most initial COVID-19 cases occurred), it was generally found to be the case elsewhere during COVID-19 where crowding and increased potential for exposure was of concern (5).

There are potential explanations for higher perceived stress among those who were asked to share their OUD medications; first, it may be the case that those with severe stress were still spending time in the "drug scene" where peers felt comfortable asking them to share their methadone. Alternatively, patients who were relatively stable yet asked to share their medications may have perceived more stress because their sobriety may have been put at increased risk if they shared. Certainly the situation of being asked to share a prescribed medication with others is a nuanced conflict for a person who is trying to abstain from opioid use.

Despite the high levels of stress reported by OAT patients, findings here point to a number of observations that bode well for the country and those using MOUD. First, despite the high perceived stress, few had relapsed or continue to use drugs. Whether this finding persisted longer into the epidemic requires further analysis. Initial data, however, shows that relapse rates have remained similar to pre-pandemic rates (22) signaling how, despite high perceived stress, patients can continue to manage their medications adequately. Patients may have been more successful in self-regulating their stress and relapse potential

because they were free from other stressors such as travel to treatment, which is often associated with police harassment (39, 40), or felt like they were at reduced risk for COVID-19 by reducing their community exposure. Second, despite high stress levels, OAT scale-up continues toward its national goals throughout COVID-19 restrictions with Ukraine achieving its highest gains in OAT scale-up in any given year (41). Successful OAT scale-up with decreased in-person interactions with take-home dosing and no increase in mortality suggest that both clinical or self-management remains adequate (22).

Though we did not measure to what extent patients in this survey received tele-health to support them during this observation period, the sheer magnitude of severe perceived stress levels by OAT patients provides information about strategies that might benefit patients when in-person contact decrease. The findings herein suggest that strategies targeted to relatively new patients in more urban settings and those who must increase their transit to OAT clinics might benefit from routine screening for stress combined with evaluation and treatment counseling using tele-health. For example, scripted telephone calls with brief counseling oriented toward managing daily challenges may reduce stress in OAT patients. A review of self-guided and clinician-guided tele-counseling strategies have demonstrated effectiveness at reducing stress during COVID-19 (42), but such strategies with OAT patients is understudied (1). Other mHealth strategies (including tele-health) may prove useful with stress management in patients with OUD (43). Adaptations for OAT clinicians might include tips on how to manage medication at home (i.e., keeping it out of the hands of others), how to respond to requests to share medication (and the consequences of personal withdrawal), how to remain socially, if not physically engaged, how to recognize and prevent overdose, how to guide peers facing similar challenges, and other targeted topics. Although not studied among individuals with OUD, these types of phone calls have been previously implemented successfully to aid in self-management of stress due to chronic conditions (44–46). The frequency of such calls may be even more helpful in urban settings, where patients experience higher stress levels.

Priority calls and or contact should be given to those newly initiated into OAT, as they may not have experience managing medications, may not yet be accustomed to side effects, and are currently experiencing higher levels of stress. Providing additional flexibility regarding hours of operation and availability of appointments for patients new to OAT may aid in allowing them more options in treatment. Given previously found associations between social support and reduced likelihood of drop-out (9, 28, 47), interventions involving close family members or friends may be considered to aid new patients. Additional flexibility regarding dosing for patients newly initiated into OAT should also be considered as they may require more frequent assessment of their dose. Engaging social workers to aid in improving the employment status of patients may also be a promising practice, as having any employment at all (even between 1 and 10 h per week) has previously been significantly associated with lower stress levels—highlighting the clinical impact of the socioeconomic challenges introduced by the COVID-19 pandemic.

Despite the many important findings herein, there are limitations. First, we lack comparable stress perception data from the period before the pandemic. While overall surveys have shown an increase in stress levels globally during the pandemic, no specific data for this population exists to make an accurate comparison. Second, it is still too early to understand the stress trajectory of OAT patients during the pandemic, especially as the pandemic evolves with new waves. It is worth noting that this study, while highlighting substantially higher stress levels among individuals with opioid use disorder (OUD) compared to the general population, does not allow us to ascertain whether these heightened stress levels are solely attributed to OUD or if the COVID-19 pandemic itself played a significant role. We plan, however, to longitudinally assess perceived stress among OAT patients as the pandemic evolves. Understanding the primary drivers of stress among OUD patients during the pandemic would be valuable for tailoring effective interventions and support strategies. Third, we lack substantive data on access to psychiatric and mental health treatment services among this population. Of note, however, urban settings have better access to mental health services, but even then, few psychiatric services are available except for patients experiencing the most severe psychiatric symptoms or illness. Future studies should seek to understand how these services may impact and affect stress among OAT patients. Last, we limited our survey sample to sites with over 400 patients. Smaller treatment sites may have more limited services, opening hours, or numbers of providers, which could have differing effects on the treatment of their patients.

Despite the challenges faced by OAT patients and stated limitations, there are several lessons learned which may aid in ensuring sustainability of OAT in Ukraine and similar settings. Primarily, reliance on in-person visits as a requirement for treatment should be reconsidered, especially for patients who have been on treatment for over a year. These findings are counterfactual to the current legal framework for OAT that existed before COVID-19, where OAT patients had substantial personal demands on them with required daily supervision over 6 months before allowing patients to self-manage themselves with take-home dosing. As a consequence of these findings, Ukraine modified Order 200, the governmental regulation for OAT, to allow patients take-home dosing as soon as 3 months after induction with three negative monthly urine drug testing for opioids. Findings elsewhere suggest that demands on patients can be reduced without compromising safety (48). These findings further support the stability of patients, even during high-stress periods strengthening the argument to allow more self-management options for patients (49). Decreasing program-level demand for OAT delivery sites will not only increase the capacity of these sites to treat more patients, but also improve treatment outcomes for existing patients (50). As the COVID-19 crisis continues to evolve, decreasing the burden of in-person visits for patients can ease the psychological and physical burdens of existing OAT patients while allowing narcologists to devote more resources to expanding access for new patients and helping newly initiated patients during their initial period of treatment. Lastly, it remains relevant to study the effectiveness of psychosocial and behavioral interventions for stress management among patients on OAT. Current restrictions due to the COVID-19 pandemic might prevent more traditional interventions, so mHealth-based interventions remain a promising and untapped resource that could help in stress management without compromising social distancing measures or imposing a significant workload on care delivery sites. Overall, the stress management among OAT patients should be prioritized and further studied, as stress remains a significant predictor of overdose and drop-out for persons with substance use disorders.

## Conclusion

In conjunction with the COVID-19 pandemic and changes to governmental recommendations to shift patients to take-home dosing, OAT patients experience substantial levels of perceived stress in Ukraine. As the pandemic recommendations subside, important lessons learned here provide insights into future strategies to consider with OAT patients as uncertainty evolves. As OAT providers in Ukraine shifted to tele-health during the pandemic, they were remarkably resilient when shifting their services in response to Russia's invasion of Ukraine in February 2022 (51–55). Moreover, the lessons learned from COVID-19 suggest that transformation in service delivery appears to have several advantages without marked adverse consequences. At a minimum, this study suggests the utility of reducing in-person demands on patients while also shifting to tele-health strategies. Reducing program level demands on patients will be important to scale-up efforts, but findings here suggest the need for innovations in tele-health to help ensure care remains accessible to patients, as it can increase their sense of autonomy while decreasing their stress levels and thus aiding in their psychological well-being. Implementation of brief behavioral interventions with family members and other individuals close to patients may be promising practices to reduce stress and therefore the likelihood of relapse and/or treatment dropout. Regular and targeted check-in calls may also be utilized to help patients in their sense of risk, and mHealth-based interventions, which remain unexplored. Yet, the most challenging and stress-inducing factors during the pandemic—i.e., employment, housing, and access to transportation—only highlight the importance of a multi-sectorial and multi-level approach to recovery, as well as how the disastrous nature of the pandemic and its effects on OAT patients and at-risk populations may only be starting to be seen. Furthermore,

the study's focus on patient stress and its impact on opioid addiction highlights the critical need for integrated mental health services within addiction treatment programs globally. It reinforces the significance of addressing the psychological well-being of individuals with substance use disorders and the role of stress in treatment outcomes. By prioritizing psychosocial support and behavioral interventions, healthcare systems worldwide can enhance their response to opioid addiction, reduce relapse rates, and improve the overall effectiveness of addiction treatment. These findings serve as a reminder that, even beyond the COVID-19 pandemic, comprehensive, patient-centered care remains essential for those affected by opioid use disorder worldwide.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by Yale University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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## Conflict of interest

AM, TF, and ZI were employed by the company APT Foundation.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

## Publisher's note

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# Introducing methadone maintenance therapy into Ukrainian prisons: a qualitative study of criminal subculture, Russia's full-scale invasion, and contested methadone objects

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**Background:** After pilot testing, methadone was newly being introduced into Ukrainian prisons in 2021 as part of a national scale-up strategy to treat opioid use disorder and prevent transmission of HIV and HCV infections. Opioid agonist therapy (OAT) scale-up in Eastern Europe and Central Asia prisons has been hampered by varying levels of influence of criminal subculture, an extralegal *informal governance* by a social hierarchy that operates in parallel to formal prison authorities. This study examined the socio-environmental factors influencing the uptake of methadone treatment in Ukrainian prisons, including changes that evolved during Russia's full-scale invasion of Ukraine and the displacement of people deprived of liberty (PDL) from conflict to non-conflict regions.

**Methods:** In-depth qualitative interviews (*N* = 37) were conducted from January 2021 to October 2022 in the only two Ukrainian prisons where methadone was being introduced with PDL (*N* = 18). These two prisons continued to provide methadone after the full-scale invasion. Former PDL (*N* = 4) were also interviewed and prison staff (*N* = 15). Interviews were audio-recorded, transcribed, and translated into English. Four authors independently reviewed, coded, and applied a phenomenological framework for data analysis, delineating themes related to criminal subculture, drug use, methadone uptake, and evolving changes during the Russian invasion.

**Findings:** Criminal subculture perceptions varied, with some seeing it as strongly discouraging drug use among certain groups, while others described it as a residual and weak influence from a more distant past. The influence of the subculture on methadone treatment uptake, however, was less clear. PDL and prison staff struggled to identify and articulate differences between illicit street-bought methadone, used recreationally, and medically prescribed methadone. Thus, the meaning of "methadone" varies in interpretation as it is being introduced, making it potentially conflicting for patients to opt into this evidence-based treatment. As Russia invaded Ukraine in 2022, PDL from conflict zones were transferred to non-conflict regions where methadone was being introduced. The prison environment became more enabling for PDL to start methadone as they were segregated and

not subject to the existing criminal subculture's rules and lacked the social ties necessary to procure drugs illegally.

**Conclusion:** It appears that the criminal subculture is variable and evolving in Ukrainian prisons and appears to be impacted differently by the invasion of Russia. As methadone scale-up in prisons expands, it will be important to distinguish the meaning of methadone perpetuated negatively by the prison subculture versus that in which it is intended as a medical treatment by the formal prison authorities. The current invasion of Ukraine by Russia provides a potential disruption to alter this course.

# Introduction

The criminalization of drug use concentrates people with opioid use disorder (OUD) and blood-borne infections like HIV (PWH) and hepatitis C virus (HCV) in prisons (1, 2). Moreover, as people who inject drugs (PWID) enter prison, within-prison drug injection often continues (3–6), including in Ukraine (7), resulting in outbreaks of HIV and HCV within prisons (8). The syndemic nature of HIV, HCV, drug injection, and incarceration (9) is especially salient in Eastern Europe and Central Asia (EECA), where, unlike elsewhere globally, HIV mortality and incidence continue to increase, fueled by the sharing of injection equipment and high rates of incarceration (10, 12).

Maintenance with opioid agonist therapy (OAT), using methadone (MMT) or buprenorphine, is the most effective treatment for opioid use disorder (13) among PWID, substantially reducing mortality and transmission of blood-borne infections (13, 14). Introducing and scaling up OAT within the prison, when combined with an effective linkage program to community treatment, contributes to country-wide scale-up of OAT as most PDL return to their communities (15, 16). Despite the increasing availability of OAT programs, they are substantially more limited within prisons and primarily use MMT as it is the least expensive (2). Until 2020, prison-based MMT in EECA, out of all countries in the EECA region, was provided only in Moldova, the Kyrgyz Republic, and Armenia (8). In 2020, MMT was introduced as a pilot study in Ukraine and Tajikistan; buprenorphine was introduced in Georgia. Suboptimal implementation of OAT within prisons, alongside the disabling HIV risk environment, the legal framework, criminal subculture, and the perception that OAT is ineffective, has undermined OAT scale-up within prisons (17). Moreover, misinformation and negative attitudes toward OAT by prison administration personnel (18) and people deprived of liberty (PDL) (15, 19–21) continue to impede scale-up.

Ukraine has the second highest number of PWID in EECA and a high HIV prevalence (19–26%) among PWID (22), making it crucial to scale-up OAT (14), including in prisons. As Ukraine introduced its first pilot methadone program to 38 PDL in a single prison starting in 2020, there was little known about the within-prison context. Within EECA, though described elsewhere (e.g., gangs in North America) (8, 23, 24), criminal subcultures exist with varying degrees of governance within the prison. These criminal subcultures include status hierarchies, and their systems of governance have the potential to greatly influence the behaviors of PDL within the prison system. Additionally, the criminal subculture provides necessary resources to PDL like personal goods that are not provided by the formal prison authorities (25). Though the social order that evolves among PDL is not entirely unique to post-Soviet nations, its presence in Ukraine (26, 27), Moldova (21), and Kyrgyzstan (28) is a particular phenomenon (29). In Moldova and Kyrgyzstan, where methadone treatment provided in prison has been present for nearly two decades, criminal subculture is described as especially powerful, and it has greatly inhibited OAT uptake (19, 28). Little data about these hierarchies in Ukrainian prisons exist and as MMT is being expanded to other prisons there, it will be crucial to understand how these informal hierarchies work and how, if at all, they may influence MMT uptake in Ukrainian prisons. Moreover, as MMT is scaled up in Ukraine, internal prison dynamics may change as a result of Russia's full-scale invasion of Ukraine, further influencing the OAT scale-up (30).

As there are data before MMT was introduced that a prison subculture existed within some Ukrainian prisons (26), this qualitative study was initially conducted as part of an implementation trial to newly introduce and scale up methadone within two Ukrainian prisons. The two prisons selected for this study are the only two where MMT was introduced before the invasion and, due to their location away from the conflict, continued to provide MMT after the war. The key question among multiple stakeholders (PDL, recently released PDL, NGO staff, and prison administrators) was to what extent might the criminal subculture influence methadone scale-up and whether the way that methadone is perceived by PDL evolves in meaning as an effective treatment for opioid use disorder or devolve as an intoxicant similar to non-prescribed drugs. As the time period involved the invasion of Ukraine by Russia, it also provided an opportunity to examine how the war influenced how receptive the within-prison context was toward methadone as individuals came under more psychological distress from the war.

# Methods

## Study setting and design

Until 2016, Ukraine had one of the highest incarceration rates worldwide. The prison census decreased from 160,000 to 49,000 by

2021 due to legislative changes and the introduction of a new probation system starting in 2016. Pre-decarceration data from 2012 showed that among PDL in Ukraine, HIV prevalence was 19.4% and 48.7% are PWID, with over a third meeting the criteria for OUD (30). No new rigorous nationally representative biobehavioral surveys have been conducted since. The 124 prisons in Ukraine are divided into those with first and recidivist incarcerations, as well as varying security levels (low, medium, and high). The pilot program to introduce methadone in PDL included 38 participants in Bucha; this prison has since closed. Plans for introducing and scaling up methadone were then planned for nine dedicated prisons and pre-trial detention centers, including the two we studied.

Qualitative, in-depth interviews were conducted with a number of key stakeholders directly or indirectly involved in the prison-based methadone program (31). The two prisons assessed were medium security and located in Central Ukraine, with one ($N = 540$) being a prison for recidivists while the other ($N = 415$) being for first-time offenders.

The 2022 invasion of Ukraine by Russia resulted in major shifts in the population. PDL from the frontline regions in the East were transported to the West, where they were housed within the western prison territories but segregated from the other original resident PDL at those prisons. This segregation was purposeful from a security perspective to reduce the potential for tension between existing residents and large numbers of newly arrived PDL.

## Sampling and recruitment

Using purposive snowball sampling (32), we identified and recruited participants from five key groups in two Ukrainian prisons: (1) prison administrators; (2) clinicians associated with the methadone treatment program; PDL either (3) receiving methadone or (4) not receiving methadone; and (5) NGO staff working outside the prison. Purposive sampling was done to identify participants with characteristics of interest (such as status in the hierarchy and experience with OAT) and to recruit approximately the same number of PDL receiving and not receiving methadone. Eligibility includes those aged ≥18 years from one of the groups and provided informed consent to be audio-recorded. With the assistance of prison administrators, prison staff—clinicians associated with the methadone treatment program and administrators—were identified and recruited from the two prisons in Ukraine ($n = 15$). Prison staff were included in this study as they consistently interact daily with PDL and could provide outsider perspectives on the dynamics between PDL. In addition, prison staff can markedly influence the shaping of the prison environment, which consequently influences the implementation and uptake of methadone among PDL. PDL enrolled in the methadone program ($n = 10$) and PDL not enrolled in the methadone program ($n = 8$) were also identified and recruited in the same two prisons. The final sample interview was conducted until saturation of themes was observed. Both PDL enrolled and not enrolled in the methadone program were included in this study as we sought diverse perspectives and wanted to identify if there were common themes among PDL who chose to engage in the methadone program versus those who did not. Participants were recruited by being called to the doctor's office by medical staff, where they were told about a voluntary research study about drug use, addiction

treatment, and health. A research assistant then explained the study to them and performed consent procedures. Participants were recruited to understand a range of experiences and perspectives, and interviews continued until thematic saturation was reached (33–37). Former PDL ($n = 4$) were also recruited as a part of this study. Former PDL were included in this study to elucidate if any unique changes in perceptions of prison-based methadone occurred post-release and reduce any potential bias of these perceptions that PDL might not want to disclose while still within the prison setting. There were two interviewers who spoke Russian (DJB and MMT) and one who spoke Ukrainian and Russian (LA). Participants chose the language they preferred to speak in. In-person interviews were conducted in the medical administrative facility. This potentially deterred some PDL of higher status from participating as it may have been seen as collaboration with the formal administration. During COVID and after the start of the full-scale invasion, interviews were conducted via video link. In video interviews, participants wore noise-canceling headphones in private rooms within the prison's medical facility.

## Data generation

Between January 2021 and October 2022, participants were initially invited to partake in a semi-structured interview guide that was expanded over time to in-depth interviews that explored how criminal subculture interfaces with drug use in the Ukrainian prison setting and how participants understood and experienced the prison-based methadone program to ensure consistency across interviews (Appendix 1). The open-ended nature of the questions allowed interviewers to inquire about the impacts of the Russian invasion when appropriate, as well as any other emerging themes. Before fieldwork, semi-structured guides were pilot-tested with one member of each stakeholder group. Data generation during the pilot test was excluded from the study dataset. The interviews were conducted via Zoom by three experienced researchers fluent in Ukrainian, Russian, and English in a private room of the prison medical facility.

## Data analysis

Thirty-six interview transcripts were analyzed as part of a single dataset, as one interview was not recorded. Professional Ukrainian translators fluent in Ukrainian, Russian, and English transcribed the audio recordings verbatim in the appropriate language (Ukrainian or Russian) and then into English for analysis. Author LA reviewed all Ukrainian and Russian to English transcripts for quality assurance. Four authors (LA, MP, MMT, and DJB) independently reviewed the transcripts and created a coding scheme relevant to the criminal subculture, methadone treatment, and the Russian invasion. A phenomenological framework was used for data analysis as we sought to understand participant perspectives on an experiential phenomenon of interest; in this case, the role of a criminal subculture within Ukrainian prisons, within the context of participants' lives. We follow this framework to ask what is meant by the phenomenon of a criminal subculture and how it operates in the lived experience of people in Ukraine to shape their relationship to methadone treatment. Subjective understandings of the criminal subculture shape

decision-making regarding the utilization of program methadone, hence the utility of this framework (38–41).

An open-coding approach was used to develop codes that would be subsequently refined through constant comparison (42). All authors discussed and agreed on the final coding scheme. Final codes were grouped into themes and analyzed using a content analysis approach (43). Finally, representative quotations were selected to illustrate the study findings and to draw out themes regarding the influence of criminal subculture on methadone treatment uptake and the effects of the Russian invasion on prison-based methadone treatment programs.

## Ethics approvals

This study received ethics approvals from the Ukrainian Institute on Public Health Policy IRB (Protocol no. 2016-031-13) and Yale University IRB (Protocol no. 1407014374). Heads of prison administration provided consent for recruiting clinicians, workers, and PDL at their prisons. All participants provided written consent to participate in the interview. A copy of the signed consent form was given to the participant for their records. All participants received de-identified study numbers to maximize confidentiality. Each participant received a hygiene kit as compensation for their time.

## Results

### Characteristics of study participants

All 37 participants interviewed in two Ukrainian prisons were included in this study. Each person invited to participate agreed and completed an interview. A summary of participant characteristics can be found in Table 1. All former and current PDL were men ($N=22$, 100%), and three staff (20%) were women. Among the 37 interviews, 48.6% were conducted with current PDL. Ages ranged from 25 to 43 years old, with a median age of 34 years. Most PDL had been incarcerated on average for 3.3 years.

### Summary of results

This qualitative study aims to elucidate the role of a criminal subculture in Ukrainian prisons where methadone treatment was newly introduced for PDL. First, we describe how informal prison

TABLE 1 Participant characteristics.

| Characteristics | People in prison (n = 18) | Former people in prison (n = 4) | Prison staff (n = 15) |
|---|---|---|---|
| Male, no. (%) | 18 (100) | 4 (100) | 12 (80) |
| Age (years), median (IQR) | 34 (31–41) | 32.5 (28.5–38) | n/a |
| Ever enrolled in a methadone program, no. (%) | 10 (55.5) | 1 (25) | n/a |

structures relate to drug use. Next, we examine conceptualizations of "street methadone" versus "program methadone." Among PDL, we observed that the two are often viewed as distinct. Street methadone refers to the methadone people obtain illegally and use outside of a treatment setting in the community (typically injected), while program methadone refers to the liquid methadone offered through methadone treatment programs. Third, we note the changing role of the criminal subculture and shifts toward more Western models of prison governance where informal hierarchies wield less power. Finally, we report on the effects of the Russian invasion on methadone treatment in two Ukrainian prisons.

### Understanding how informal prison structures relate to drug use

There was variability in the perception of the strength of the informal prison governance. While several participants acknowledged the existence of informal prison structures among PDL, others rejected the notion that criminal subculture heavily influenced PDL's drug use. PDL described these structures as hierarchal, with many reporting being from either the low or high caste. The hierarchy is as follows: Thief in Law, *blatní* (leaders of the prisons), *muzhyký* (largest class, laborers), *kozlý* (those who have been demoted for cooperating with the prison administration), and *opúscheni* (bottom of the hierarchy and no longer follow the rules, "untouchables") (Figure 1). In some cases, participants suggested that the status in the hierarchy they occupied could influence their ability to use drugs. Those higher up in the hierarchy typically have more restrictions on their drug use. In contrast, the lower-status PDL have more freedom as it pertains to drug use. One person from a lower caste remarked that they were free to use drugs if they chose to do so.

"Well, my caste is the lowest in the hierarchy, here. I mean, I communicate well with the highest hierarchies. Very good, because I set myself up like this. I mean, in my case, it doesn't matter. I mean, me, yeah, if I'm gonna do drugs of any kind, no one's gonna tell me anything. Here, but maybe there are others to whom they may say something…" —Vyktor (PDL not enrolled in OAT, 29 years old, Prison A).

In contrast, prison staff reported the opposite. Prison staff thought that PDL who occupied lower castes in the hierarchy were forbidden to take drugs and that those higher in the hierarchy could use them more freely.

"Talking about the hierarchy, it is blatní and their environment that basically have access to injectable drugs… It is generally not allowed for the opúscheni and for an ordinary hard-working prisoner according to the hierarchy of the colony. They can get punished for it by their own folk…" —Leonid (clinical staff, Prison A).

Participants would refer explicitly to the "thieves' law" or "thieves' code." This code governs criminal subculture and sets limitations on all aspects of life, including drug use. In contrast to low-status PDL, some participants explained that PDL belonging to higher levels in the hierarchy were not allowed to use drugs.

"The problem is that, according to their, let's say, thieves' laws, the blatní is the one who looks after the unit, after, well, and so, there,

FIGURE 1
Informal criminal code hierarchy in Ukrainian prisons.

they do not have the right to use any narcotic substances. They decide, as they say, people's fates, they have to be of sound mind. Thus, drugs are forbidden for them on the whole. It is forbidden to use any drugs according to their laws…" —Mila (prison administrator, Prison B).

Drug use appeared prohibited among the higher-ups because they had more influence and responsibility over others' "fates," alluding to the governing responsibility of the higher-ups and the potential for drug use to disrupt their governance. It also was part of a moral code that was expected of those in the hierarchy.

"Like, not everyone should use [drugs]. Understand that, we have a hierarchy in this system. You know? From the little person to the big one. If he's a big man, he decides people's fates – he can't use. He can't use even a small amount, he must have a 100% consciousness. So, he can't use and he won't use" —Anton (PDL enrolled in OAT, 34 years old, Prison B).

Other participants noted that their drug use could threaten their position in the caste system. This phenomenon was described among those in higher castes.

"R: In general. According to the notions, the blatní cannot be using. When I started using it, I was no longer there…They didn't want to push me away, but I said I was using myself…

I: When you started using again, once more, were you able to stay in that caste?

R: I stayed, but unofficially, everyone knew I was there, but I didn't shout out about it, figuratively speaking. But according to our law – it is impossible. You have no right" —Vamava (Former PDL not enrolled in OAT, 36 years old, Prison B).

Some remarked that methadone treatment, specifically, was not an exception to this rule. Methadone treatment was likened to using drugs and was therefore prohibited among members of the informal prison hierarchy. The criminal subculture, in some instances, was understood to dissuade or actively stop PDL from entering methadone treatment.

"Well, each society has its understanding of life and has its principles and concepts that they would not want to be crossed… and they don't want to allow, for example, those from the [methadone] program to be among them. They will achieve this by some other methods, and so on. There, bypassing the police, not listen to the administration" —Aleksander (former PDL enrolled in OAT, 28 years old, Prison A).

"Well, they [the hierarchy] are basically against it. They do not welcome drug addicts in their circles, well … There are people who use, but they kind of do not welcome it all. Opium is possibly okay, but methadone… not, in their own circles" —Peter (former PDL not enrolled in OAT, 40 years old, Prison B).

While some participants did note the role of the thieves' code and the criminal subculture in delimitating rules surrounding drug use, others rejected this notion. Some explained that the rules of the hierarchy have begun to take a "back seat." Consequently, seeking methadone treatment among some PDL was not understood to be at odds with the informal hierarchy.

"There's no such thing [as the hierarchy] now, now if you cooperate with the administration, you cooperate. If you want to be treated [with methadone], you can be treated, no convict will say anything to you, because now all these their concepts, their beliefs, have started to take a bit of a back seat… If the convict wants to be treated, let him be treated" —Mila (prison administrator, Prison B).

The study prisons were located in western or central Ukraine, and the Russian invasion began in the East. As a result, PDL in the East were transferred to central or western prisons as Russia continued to move in on eastern Ukrainian territory. The prison in Vinnytsia was cordoned off to allow for PDL from the East to be housed but segregated from the locals. New PDL who were recently transferred to western prisons from the East because of the war also noted the limited influence of the criminal subculture.

> "We lived like people. And here it's not clear at all. The blatní here, they have some kind of rules, but no one respects them" —Taras (newly transferred PDL not enrolled in OAT, 32 years old, Prison A).

## Conceptualizations of street methadone versus program methadone

Interviews produced blurred boundaries between "street" (illegal) and "program" (prescribed) methadone. Program methadone refers to the liquid methadone administered by prison clinical staff that is given to PDL participating in the prison-based methadone treatment program. Many struggled to identify and articulate the differences between street and program methadone, although they acknowledged the two were different. Methadone was conceptualized by some as a nameless, ambiguous substance.

> "Well, we call it methadone. But it's not that kind of methadone… Well, crystal, it's methadone… they just call it crystal, and actually they call it methadone too, but it turns out that methadone is a little bit another concept, as I already understood after the lecture… That's the problem, it doesn't have any particular name, this drug" —Mila (prison administrator, Prison B).

Prison staff reported that some PDL would consider the program methadone a "legal drug." To delineate the difference between street and program methadone, some prison staff would try to differentiate the two by providing information on the medicinal effects of the program methadone.

> "Some inmates ask, 'are they going to give us legal drugs?' I explain to them that the methadone they're going to give you, it's not that kind of drug, it's just going to block those receptors that cause you to have that craving for drugs" —Mila (prison administrator, Prison B).

During interviews, participants often explained that they were not on "methadone" but, rather, "street methadone." The greatest differences between the two are how they were taken and their concentration—street methadone was injected, bought illegally, and more concentrated. In contrast, program methadone was imbibed under clinical supervision.

> R: No, I wasn't on any methadone. I was on, like you said, street methadone, yeah.
>
> I: What do you call it if it's not street?

> R: Methadone.
>
> I: Just methadone?
>
> R: Yes.
>
> I: And your opinion or that of others, what is the difference between program methadone and street methadone?
>
> R: Well, for example, program methadone, we drink it, right? And street methadone, we shoot. That's the difference. And the difference is great —Vyktor (PDL not enrolled in MMT, 29 years old, Prison A).

The same participant continued to say that he could differentiate the different highs between the two forms of methadone. This was understood to be, in part, due to how the drugs are taken.

> R: Yes. From the program methadone, is not high. It acts in about twenty minutes, half an hour. And the street – it immediately acts, because through the vein injected, here. Although through the vein when injected with street methadone it evaporates faster, that is, it passes faster, the effect. And street methadone keeps longer.
>
> I: Does the street methadone? keep longer?
>
> R: Yes. Because it's absorbed into the stomach. So it keeps longer. I mean, it's different. And in the other thing, I don't see the difference —Vyktor (PDL not enrolled in OAT, 29 years old, Prison A).

Other participants felt that street methadone was more addictive and worse for the body. Additionally, participants noted the social stressors that accompanied street methadone, such as financial concerns and potential jail time, and described methadone as free of these consequences.

> "Firstly, more addiction, more pulling [from street methadone], it's worse for the body, much worse than the program [methadone]. And firstly, this is a constant problem, looking for money, not working, there is no way to support yourself. When you're on drugs, there's nothing you can do. It is easier for people on the program, they can work already, they can just get their dose, and they don't have to look for money or problems. It doesn't lead to jail" —Aleksander (former PDL enrolled in OAT, 28 years old, Prison A).

Furthermore, as "street methadone" availability preceded the introduction of program methadone, the participants began to conflate them, believing in some instances that they were the same. In contrast, others believed them to be different. This blurring of meaning has the potential to disrupt the way that methadone provided within a treatment program could be as negative as illegal "street methadone" and undermine uptake. One participant considered the physical sensations the same but noted that taking methadone through

the treatment program transformed the psychological and mental experience.

> "Although they say that methadone, well, the OAT program, the drug is the same crystal methadone… on my own, I can say that's far from true…The feelings are the same. Although physically the same, but psychologically and mentally [different] when you sit in the system" — Ehor (PDL enrolled in OAT, 43 years old, Prison B).

Prison staff commented on how the program methadone, administered by the prison staff, may be uniquely conceptualized among potential users. While drug use in prison occurs, it was understood to be prohibited by the PDL's subculture, and it was unclear whether methadone fit into this framework as an "illegal" drug or a medication prescription. The legality of using methadone among PDL was further complicated by the fact it was distributed by the prison administration. This, in turn, may have been seen as cooperation with the administration, which would threaten one's position in the prison hierarchy.

> "The inmate's main point of concern is, especially if he is, so to speak, on the other side of the barricade, that he will become vulnerable and weak after joining the treatment program… And it corresponds with the culture. It's contraband, it's under the proper inmate culture, let's say so, this is normal. But methadone is different, it's a legal narcotic, it comes from the prison administration. It's distributed by the administration. If it was done by an outsourced doctor, well, perhaps it would somehow be different. It could be something totally different, it could be cool, you have a doctor from the outside making daily visits. A doctor from the outside comes to you and gives you, like, narcotic drugs. But, it's like, it's a whole different ball game…" —Stepanida (NGO staff).

The program methadone is conceived as being different in terms of how you ingest it, its intoxicant properties, and how it is conceived as a drug versus a medication, but it was still difficult to disentangle from street methadone. Prison staff also struggled to separate street and prison methadone. The differences observed evolved from a moral and legal standpoint rather than disentangling how the two substances differed in terms of euphoric effect, how it is taken, and how it is obtained. One participant expressed their frustration that someone could be imprisoned for dealing drugs and then receive methadone legally in prison.

> "Well, what do you think if, bloody hell, if the two medics are involved in something like that and then we get this as well. Two people are in for dealing drugs, so here have some methadone as well, like, I haven't seen anything like that before, I cannot wrap my mind around it… Two staff members at the medical unit are involved in dealing drugs, and they also get a kilo of methadone, here you go, here's for you to distribute in the framework of some program" —Inessa (prison administration, Prison B).

On the other hand, some prison staff viewed methadone as a purely medical treatment, separate, and different from other illicit drugs in prison.

R: They can't just get drugs in and inject them without permission. If they want permission, they have to pay.

I: Methadone including? Is methadone included?

R: Methadone is purely… medical… — Leonid (clinical staff, Prison A).

## Prison life beyond Soviet legacies: shifts away from criminal subculture

Many participants commented on the existence of different prison governing systems. More specifically, the existence of "black" versus "red" prisons, or prisons run primarily by PDL versus prisons run by the formal administration, respectively—a distinction that exists throughout the post-Soviet space. Though the Ukrainian prison system is perceived to have been transitioning more toward "red" prisons that espouse organization and treatment more aligned with Western Europe, a legacy from the Soviet system remains in part in the prison system. Prison staff considered administration-run prisons a more European model and PDL-led prisons a Soviet model of prison governance. Some staff, however, felt that Ukrainian prisons still followed a Soviet model and were, therefore, poorly equipped to host methadone treatment programs:

> "You are perfectly aware of what the difference between our Ukrainian and European intellect is. They can give drugs to European convicts and would rather not give them to ours. Because their convicts fear the administration, whereas our convicts can do harm. This is a threat to the lives and health of workers and convicts themselves" —Stefan (clinical staff, Prison A).

Criminal subculture, however, was understood to be shifting toward a "western" model. Although not extinct, the deterioration of the informal prison structure was seen as symptomatic of a shift toward Europe.

> "The biggest one [thief-in-law] in the hierarchy is almost gone. We are moving forward, we are going to Europe. And in Europe, there is no such thing" —Vyktor (PDL not enrolled in OAT, 29 years old, Prison A).

Participants often considered this shift away from red and black prisons not only as a movement toward Europe but specifically as a shift away from Ukraine's Soviet past. This has been an especially salient trajectory for Ukraine since Russia invaded Ukraine in 2014 and illegally annexed Crimea.

> "A lot has changed, probably. We became more independent from our Soviet past. From the gulag culture and so on. There is more humanity now" —Stasya (clinical staff, Prison B).

The hierarchy's perceived diminished influence was understood as a result of this cultural shift.

"I believe that 20 years ago the prison hierarchy was much more rigid, the inmates themselves followed those rules and supported the hierarchy with much more vigor as compared to now. The rules themselves are being simplified, the people are changing, I believe that 20 years ago the inmates much more closely followed the rules and stayed true to the lifestyle. Nowadays, the people have changed, and I know that the hierarchy's impact has diminished. Perhaps it has changed because the world is changing, and it has impacted the hierarchy" —Nyusha (clinical staff, Prison B).

Some felt that the diminished influence of the hierarchy, due to the observed cultural shift, manifested in the form of more relaxed rules surrounding selling and using drugs among PDL. Additionally, participants felt a more egalitarian social order was forming among the PDL.

"For example, if someone sold drugs, he was considered lower and could no longer consider himself a normal convict. There is no such division now… They used to be called hucksters in prison slang, who had traded in drugs, so they could not talk to others. It was in 2007, 2008, and 2009. Now they are all equal. That's how it is" —Dobrushin (prison administrator, Prison A).

## The effects of the Russian invasion on methadone

After the 2022 Russian invasion, many Ukrainian prison populations were displaced and transferred to prisons in more western regions. The local people in prisons (i.e., non-displaced persons) commented on the large swaths of PDL newly placed in their prisons, and they had the perception that there were distinct cultural differences in which the new individuals were more aligned with Russia.

"They [recently transferred people in prison] have a different way of thinking, their mentality is more like Russia. It is the Russian mentality. If Russians had come after them, there was that zone, they would have taken machine guns and gone against Ukrainians. And they were offered methadone, they were given food and water" — Artur (PDL not enrolled in OAT, 25 years old, Prison A).

Other participants describe that these new transfers arrive with withdrawal symptoms, potentially as their illegal drug supplies were interrupted. These individuals are often transferred from prisons that lack methadone treatment programs and are perceived as having a higher need for methadone and, therefore, more readily engaged with the methadone treatment program.

"Well, look, now I'll tell you something interesting. Due to the war, the current one, a zone was transported from Zaporizhzhia. One hundred and twenty people came here… And they all came; Well, not all, but not a small mass with withdrawals. Here they are put on the program, yes. They didn't have this program" —Ehor (PDL enrolled in OAT, 43 years old, Prison B).

New transfers were described as less well-connected than the local PDL. This, in turn, limited new PDL arrivals' ability to procure drugs illegally. Consequently, their greater participation in the methadone treatment programs was understood to be a result of necessity.

"They [transferred PDLs] came here, again, a new place, and as we said, it's not so easy to get it [methadone]. Especially for the new people, nobody's going to tell them these ways of getting high on methadone, let's say street methadone, nobody's going to tell them. Because new people, everybody's afraid to tell their secrets, right. So it's like, I've seen them feel bad, they've been starting to get kumar, they've realized that they can't find the drug fast enough and so they've decided to get into the programs" —Olek (PDL not enrolled in OAT, 43 years old, Prison A).

New transfers confirmed the perceptions of others as they reported enrolling in the methadone program after their arrival.

"I: So, let me get this straight: you abused [drugs] a lot, you were arrested, you went to jail, where you stopped abusing from one day to the next?

R: No, I stopped using it here in the camp.

I: Oh.

R: Well, I came here from the pre-trial detention center, and I started a program, this one here, methadone.

I: Yeah, yeah.

R: And in the jail, I was using, yes. We've been doing it there, there's no program in the pre-trial facility —Roman (recently transferred PDL enrolled in OAT, 34 years old, Prison B).

## Discussion

Our findings point to new insights into how criminal subculture in Ukrainian prisons relates to illegal drug use and evidence-based treatment. While most participants did acknowledge the existence of an informal hierarchy among PDL, perceptions of its influence and strength of this influence varied and appeared to be waning over time. In some cases, the criminal subculture was understood to vehemently prohibit drug use, particularly among those of a higher caste. In contrast, others felt the criminal subculture was waning and, therefore, had less ability to dictate a person's within-prison drug use. Whether methadone treatment and even illegal drug use were supported by the informal hierarchy was also ambiguous and in flux, especially as there was the perception of moving toward a more European perspective. This, in part, is reflected in the data in which PDL and prison staff struggled to identify and articulate differences between street and program methadone and how the meaning of street methadone can be transformed when administered in prison settings. Finally, the Russian invasion seemed to impact the uptake of methadone treatment programs as newly transferred PDL were understood to have more need, especially as they were observed to have psychological

distress from being on the frontline and experiencing symptoms of withdrawal. Consequently, displaced PDL were more likely to engage with these programs, potentially as the prison subculture did not interfere. It appeared that the informal hierarchy provided some empathy toward them by virtue of their proximity to the war and did not actively dissuade them from treatment. To the best of our knowledge, these were the first interviews ever conducted in Ukrainian prisons during wartime.

While we cannot fully explain why the influence of the criminal subculture is waning, there are a few possible explanations. First, each of the countries of the former Soviet Union has had its own distinct political, economic, and social trajectory, which may, in turn, impact the criminal subculture. For example, the influence of the criminal subculture was nearly erased in Georgia, where there were major economic and anti-corruption activities, which markedly reduced the influence of the prison hierarchies (29). The situation in Ukraine, however, may be different as Ukraine distinguished itself early from Russia through its Orange Revolution in 2004, where it denounced Russia's influences in its political process. The trajectory of Russia and its continued perpetuation of the criminal subculture departed further when Russia invaded Ukraine in 2014 and annexed Crimea. This departure from Russian policies grew further, as observed here, when Russia invaded Ukraine again in 2022 with a full-scale war.

Parts of our data regarding the criminal subculture in prisons in Ukraine are consistent with the literature from other EECA countries like Moldova and the Kyrgyz Republic, which illustrates how criminal subcultures can inhibit the uptake of prison-based methadone treatment programs (18, 21, 44). Ukraine, however, differs from these countries, where methadone had been introduced in prisons nearly two decades ago. The role of the prison subculture throughout EECA has evolved. At some points, the prison subculture operated the drug trade from an economic perspective. Later, some hierarchies outlawed the trade, but in the case of Kyrgyzstan, the hierarchy provided liquid poppy straw (an opioid) every 10 days as payment for loyal workers.

Findings here, however, resonate with data elsewhere that drug use is prohibited by the thieves' code and can be actively enforced by those who occupy a higher caste via ostracization (19). As methadone is newly being introduced as a medical treatment, methadone appears to be emerging as a formal version of street methadone, not sanctioned as a medical treatment and therefore something not to be trusted. An alternative explanation for why MMT is mistrusted by some PDL is that the prison subculture often mistrusts any activities they do not control, a finding observed in Kyrgyzstan (45). We found, however, that the thieves' code was applied more harshly to PDL belonging to higher castes, which limited their participation in methadone treatment programs. Among those that occupied lower castes, there was more flexibility surrounding drug use. There was not a clear consensus on whether using program-delivered methadone was considered against the informal hierarchy's rules.

Of importance is the observed conflation between "street" and "program" methadone, which may explain the lack of consensus as to whether the program-delivered methadone qualified as an illicit drug or a medication. Even outside prisons, negative attitudes toward methadone as treatment exist (36). Interviewers also struggled to identify which type of methadone (street vs. MMT program) participants were referring to as participants would use the terms interchangeably. Rhodes et al. noted that there is "no single biomedical object of methadone…" in the East African context (46). Our findings echo this sentiment as we illustrate how understandings of methadone traverse various conceptual

topographies in Ukrainian prisons, and it can be considered a drug that induces euphoria, an addiction treatment, or a "legal" drug with reduced psychoactive potency. Future prison-based methadone programs should, therefore, consider hosting joint, formal education and counseling sessions with both prison staff and PDL to help distinguish between prison and street methadone and correct any misconceptions about program methadone. Additionally, participants noted that delivering methadone through the prison-based program transformed the experience of the medication itself. Some participants used language that suggests the methadone program is a form of biopower held by the administration that further transforms the object. Specifically, the statement, "he will become vulnerable and weak after joining the treatment program… It's distributed by the administration. If it was done by an outsourced doctor, well, perhaps it would somehow be different." In a prison setting, where people with substance use disorders have no choice but to cooperate with those who wield power over them to receive treatment, methadone may be understood as a form of social control over drug users (47, 48). Consequently, the fear of this observed social control both transforms the object of methadone and may dissuade potential participants from engaging in methadone treatment.

The invasion of Ukraine by Russia has the potential to transform both the prison subculture and the perceptions of methadone as a treatment. While the government has clearly aligned itself more with the West during the violent invasion of Ukraine by Russia, it may have the potential to interrupt the existing perception of program methadone being conflated as street methadone and further support its scale-up. At least on the surface, it appears that the early trajectory is to potentially transform methadone as a treatment. However, within prison, training and peer training may be needed as prisons are often insulated from perceptions outside this "hidden" context.

Despite many of our findings aligning with other prison-based methadone program studies, Ukraine's prison setting was unique as it appeared to be "in transition" away from criminal subculture-dominated prisons and not as easily categorized into black versus red prisons. This may bode well as methadone is scaled up within prisons, and there is the perception that people become healthier. Alternatively, as was observed in Kyrgyzstan, PDL on methadone were also provided "dimedrol" (diphenhydramine), resulting in the deteriorating health of methadone patients and undermining methadone as an effective treatment (49). Previous research on prison structures in Kyrgyzstan notes that national political stability and regimen transitions are often mirrored within the prison walls of a nation (50). Our qualitative data reveal a similar pattern within Ukrainian prisons, and methadone treatment may, therefore, become intertwined with local politics. Not only did participants observe and report shifts away from informal prison hierarchies, but they also explicitly mapped this diminishing structure as Ukraine left its Soviet past behind and moved toward Europe. Outside of prison facilities, Ukraine's shift toward Europe has also materialized in its pursuit of European Union (EU) and NATO memberships (51, 52). This finding underscores the importance of understanding inter- and intra-national politics that may impact the implementation of health interventions.

Finally, we explored the effects of the Russian invasion on the Ukrainian prison-based methadone treatment programs. We found that recently transferred PDL were perceived as more aligned with Russian identity and more likely to participate in these programs. Non-displaced PDL understood this to be a result of necessity, as newly transferred PDL were less likely to have existing social ties that

would enable them to access drugs through other means. This finding may also be reflective of Emergent Norm Theory, which stipulates that "non-traditional behavior develops in crowds as a result of the emergence of new behavioral norms in response to a precipitating crisis (53)." While our data, coupled with Emergent Norm Theory, suggest methadone treatment is frowned upon by some PDL in this setting, newly transferred individuals have not yet been socialized in this environment. They are, therefore, unimpacted by predominant norms, which may explain relatively high perceived uptake.

While prison transfers across borders heightened perceived participation in methadone programs, the Russian invasion of Ukraine placed the country's methadone programs in peril (54). Within a week of Russia's illegal annexation of Crimea in 2014, all methadone clinics in the region were permanently closed. The closures left 800 patients stabilized on methadone at the time without access to life-saving medication. Many of the methadone patients chose to migrate to non-occupied territories. For 10% of the patients, however, the closures proved fatal as withdrawal from methadone led to suicide, opioid relapse, and fatal overdose (55). While access to methadone has temporarily increased for those transferred out of Ukraine, within their own country, methadone is in danger of prohibition, a devastating outcome that will increase rates of HIV/HCV, overdose, and unregulated injection drug use and permanently deny access to life-saving medication.

Despite these important findings, there are some limitations. First, we only conducted interviews with PDL and staff from two prisons in the western region. These two prisons were the first ones to introduce methadone after the initial pilot program that has since closed. Qualitative data are highly contextual and hypothesis-generating, so our findings may not be generalizable to other PDL. Second, social desirability bias may have impacted the data gathered. Despite interviewers making it clear that they were not associated with the prison administration, PDL may have assumed that research staff would share information about drug use with the formal administration. Consequently, participants may have been less likely to disclose details of their lives and habits that went against the law.

## Conclusion

The evolving relationship between criminal subculture and a nascent methadone program in Ukrainian prisons appears to impact the understanding and uptake of MMT programs among PDL. During this process, it will be important to initiate education programs for PDL and custodial staff to recognize that two forms of methadone exist and compare and contrast them in terms of their impact on health, with one having greater potential to harm if not dosed adequately. The Russian invasion also provides a unique context for program rollout as it may function to rapidly shape methadone into a more well-defined object. It is critical that as prison-based programs continue to grow, they account for the changing influences of criminal subculture as Ukraine progressively makes political and social shifts toward the West.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

The studies involving humans were approved by Ukrainian Institute on Public Health Policy IRB and Yale University IRB. A certificate of confidentiality was provided by the National Institutes of Health to protect participants. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1227216/full#supplementary-material

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# Qualitative exploration of the early experiences of opioid use disorder patients from private clinics after Russia's invasion of Ukraine in five major cities in Ukraine

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**Introduction:** Following the full-scale invasion of Ukraine by the Russian Federation on 24 February 2022, over 6,000 patients were at risk of potential disruptions in treatment with medications for opioid use disorder (MOUD) in Ukraine. Before 2022, privatized MOUD clinics had emerged, partly driven by restrictive governmental policies and practices in state-funded facilities. Nevertheless, scant information exists regarding their operation and the patient's experiences, especially during crises. This study seeks to elucidate the initial lived experiences of patients utilizing private MOUD clinics, integrating these insights with an analysis of the responding health system during war.

**Methods:** The findings are derived from 20 qualitative semi-structured interviews conducted between March and June 2022, engaging participants from five major Ukrainian cities: Kharkiv, Kyiv, Odesa, Poltava, and Zaporizhzhya. Employing a rapid analysis procedure, we examined the data through descriptive and analytical summaries aligned with the domains of the data collection instrument.

**Results:** Emergent themes encompassed stress and uncertainty following the invasion's onset, challenges accessing MOUD, and consequent perceptions concerning state-funded versus private clinics. The study identified disruptions in the operation of private MOUD clinics across most cities examined. Issues pertaining to MOUD medication availability were linked to dosage reductions at state-funded clinics or pharmacy medication shortages or closures. Despite varied experiences at different MOUD clinics and cities, most participants continued their treatment.

**Discussion:** This qualitative exploration provides a perspective on lived experiences with MOUD treatment at private clinics amidst the initial months of the invasion, illuminating how the early days' stress, access challenges, varied responses from private MOUD clinics, and precarious conditions informed or altered preferences regarding MOUD treatment options. Moreover, these findings corroborate previously documented efforts by myriad stakeholders to mitigate war-related disruptions to MOUD delivery. These insights contribute to the international understanding of health system navigation and resilience during major crises, offering valuable lessons for preparedness development.

KEYWORDS

opioid use disorder, methadone, medications for opioid use disorders, resilience, war, Ukraine, health emergency

# 1 Introduction

The onset of the full-scale invasion of Ukraine by the Russian Federation generated diminished access to healthcare services and medicines nationwide. The reduction in access is particularly pronounced for residents near the front lines, in areas under partial Ukrainian government control, and among the internally displaced populations (1–4). Since the invasion began on 24 February 2022, there has been an exponential rise in the number of internally displaced people (IDPs), as reported by the UN Refugee Agency (UNHCR). As of June 2023, over 7.7 million individuals have been displaced, constituting 17.5% of the population. These displacements further exacerbate the stress on healthcare access and services (5, 6).

When the Russian Federation launched a full-scale invasion, over 17,000 patients nationwide received methadone or buprenorphine as their medication for opioid use disorder (MOUD) (7). In a month of a full-scale war, over 2000 patients faced the risk of MOUD interruption: at least 57 governmental MOUD clinics throughout Ukraine either stopped operating, were destroyed by shelling, or ran out of medications. Considering the total number of MOUD patients (over 17,000 at state-operated facilities and thousands more at private clinics), over 6,000 patients were at risk of treatment interruption in Ukraine (7).

War invariably leads to the immediate displacement and dispersion of people, uprooting lives and scattering communities in every direction. Displacement (8), the forced movement of people from their usual environments, and related dispersion—the distribution of displaced persons to different locations—perpetually complicate and disrupt the provision and continuity of healthcare services, making access to essential medical care a significant challenge. This is especially true for most MOUD that must be taken daily, without interruption, or patients will experience symptoms of abstinence, psychological distress and suicidal ideation and may lead to substance use relapse, overdose and death (9), which is what happened when Russia illegally annexed Crimea and banned all MOUD (10, 11). The UNHCR stresses that in crisis settings, where life-or-death allocation decisions are made under the principle of maximizing the greatest good for the greatest number, there is a need for an inclusive, deliberative, consistent, transparent, and technically sound decision-making process (8, 12). Implementing such a framework proves challenging, especially in diverse and often poorly governed environments (12, 13).

Wars and other devastating circumstances often overwhelm health systems, yet the Ukrainian health system continues to function despite the ongoing major shock stemming from the ongoing full-scale invasion. According to WHO estimates, the country's health system has demonstrated resilience, maintaining overall high access to certain health services (1–3). The September 2022 estimates indicate that 95% of Ukrainians reported receiving primary care services among those seeking care, while up to 90% had access to health services for chronic conditions (3). Nonetheless, individuals with substance use disorders (SUDs) are particularly vulnerable during crises followed by displacement and risk disruptions in access to critical services and treatment (14, 15).

War introduces significant challenges to medication access due to supply chain interruptions, the closure of health facilities, and the displacement of the healthcare workforce, leading to reduced availability and accessibility of essential medications (12–17). Furthermore, displaced individuals often face substantial barriers in accessing medications, stemming from legal, financial, and logistical issues. The lack of stable housing and proper documentation often aggravates these challenges (12–15, 17). The trauma and stress associated with experiences of war and displacement also exacerbate mental health needs, leading to an increased demand for related services and medications—resources often scarce in such settings (18, 19). Additionally, there is evidence that IDPs experience higher mortality rates and worse health outcomes compared to host communities and refugees, with social determinants of health and limited access to essential health services as key drivers (18).

According to governmental reports and published studies related to the first few months following the initial invasion, the main challenges in MOUD provision were either real or perceived depletion of MOUD medications and the risk of supply interruptions, disruptions in data flow about existing supplies, the risk of closing MOUD clinics due to military activities, the destruction of health facilities and infrastructure, the occupation of the territories, and the displacement of MOUD patients and MOUD providers (4, 14, 20). Furthermore, on the fourth day of the invasion, Ukrainian borders were closed for all adult men under 60, increasing stress as men remained while their families fled Ukraine. This closure significantly affected patients with MOUD, as only those with certain levels of disabilities were permitted to leave. In rare instances, when these men left, they were provided with their medical records, history of treatment with MOUD, and contact information for MOUD treatment clinics in their destination countries at their original MOUD treatment clinics to facilitate prompt resumption of MOUD treatment upon arrival. Despite these initiatives, evidence suggests that sustaining MOUD treatment encounters challenges (21).

One recent study reported on governmental efforts to sustain MOUD treatment during the first year of the war, including important legislative changes and the mobilization of efforts that safeguarded treatment for thousands of MOUD patients across Ukraine; however, it acknowledged that there are limited data about those receiving MOUD from private treatment clinics in Ukraine (15).

Starting at the end of 2016 with changes in the legislative document guiding MOUD delivery, private MOUD treatment clinics emerged in parallel and, to some extent, as a reaction to restrictive government policies and practices in narcological facilities (22, 23) and patients' willingness to pay for services to avoid such restrictions (24). These private clinics emerged as a practical approach to counteracting the restrictive practices within governmental clinics and addressing the unmet demand in MOUD (25–27). However, scant information is available regarding the operation of private MOUD treatment clinics, and even less is known about their response to the crisis precipitated by the war aside from one case report describing clinics in Kharkiv collaborating with government clinics (28–30).

This research analyzes the initial experiences of MOUD patients from private clinics within the context of the health system's response to the Russian invasion of Ukraine on 24 February 2022. Through a systematic examination, this analysis elucidates the connection between patients' lived experiences and the healthcare system's counteractive measures implemented in the early wake of the invasion.

## 2 Methods

This study draws upon qualitative, semi-structured interview data collected as part of a more expanded implementation science research endeavor to understand the lived experience of people receiving MOUD in private settings in Ukraine at the onset of 2022. Data were collected from participants residing before the onset of the full-scale invasion in five major cities in Ukraine: Kharkiv, Kyiv, Odesa, Poltava, and Zaporizhzhya, which are representative of Ukraine's Eastern, Northern, Central, and Southern regions, respectively.

We conducted a total of 20 interviews with individuals receiving MOUD medication at private clinics before the full-scale invasion of Russia on 24 February 2022. We recruited participants via targeted sampling, facilitated through direct collaboration with partner non-governmental organizations (NGOs) providing services to MOUD patients and participant referrals. Our team engaged social workers from partner NGOs at MOUD treatment clinics in each selected city. We provided these workers with the inclusion criteria for potential respondents and the contacts of the interviewer (AM-2) in case the respondent wanted to reach out directly. Social workers also provided contacts for potential participants after prior agreement with them. When the interviewer approached potential respondents directly via phone, there were no refusals to participate. We provided incentives to social workers for the recruitment (~3 USD). During data collection, we purposefully recruited to ensure geographical representation, socioeconomic characteristics, and a diverse participant pool from various backgrounds and regions. Participants were compensated ~14 USD for their time.

Only adults 18 or older receiving MOUD at a private clinic before 24 February 2022 were eligible. Before the interview, each study participant received extensive information about the study. Eligible participants provided oral consent. Interviews were conducted and recorded during online calls using the preferred messenger application, at times convenient for the participants, and either in Ukrainian or Russian based on the participant's preference. Video conferencing was not utilized. Each interview, lasting approximately 30 min (AM-2), was conducted by an experienced researcher with substantial experience in qualitative interviewing of MOUD clients. We collected the data between March and June 2022. The semi-structured interview guide included the following domains: (a) pathways to MOUD treatment; (b) MOUD experience in private clinics; (c) MOUD experience since the beginning of the war; (d) current experience with MOUD; (e) other observed experiences with MOUD; (f) knowledge of the availability of illegal drugs since the full-scale invasion; and (g) social support for MOUD treatment. All audio recordings have been de-personalized; pseudonyms have been assigned to each interview, and these pseudonyms are used in quotes. For this analysis, the quotes were translated into English and back-translated into the original language by two research team members independently to ensure the quote's essence is not lost in translation.

This study was reviewed and approved by the Institutional Review Boards at the Ukrainian Institute on Public Health Policy (Submission id 2019-009-04).

The interviews were recorded, and data were analyzed directly from the audio recordings using descriptive summaries and the domains of the data collection instrument. Further data analysis focused on summarizing and comparing participants' experiences from different cities and developing analytical summaries (31).

Analysis was performed following a rapid assessment procedure (RAP) strategy (32), which organizes and summarizes the data according to a pre-defined framework. The steps of data analysis were as follows: (1) The data analysis team (AM-1, AM-2, and IP) listened to two interviews and agreed on key terms for the categorization within the RAP matrix that addressed the study's aims; (2) AM-1 developed the categorization matrix pilot-tested by the data analysis team using three interview records to finalize the matrix; (3) AM-1, AM-2, and IP listened to all interviews and summarized them according to the matrix, which resulted in three individual matrices summarizing all the interviews according to the categories; (4) The data analysis team met to discuss differences and commonalities in the individual matrices; and (5) AM-1 combined matrices following the discussion and noted any disagreement in summaries. Discrepancies were assessed by the analytical team and resolved through iterative discussions. The final matrix was used to compare experiences by city and map findings into analytical categories described in the results section alongside key healthcare system's counteractive measures.

## 3 Results

### 3.1 Participants

Table 1 provides the sampling of MOUD participants from private clinics in five major cities (Kyiv = 6, Kharkiv = 7, Poltava = 3, Odesa = 3, Zaporizhzhia = 1), and Table 2 provides the demographic and clinical characteristics before and soon after the invasion. One participant was female, and the majority were in their 30s and had initiated injecting drugs over 10 years before being prescribed methadone ($n = 15$) at a median dose of approximately 130 mg (12 mg for those taking buprenorphine). Before the full-scale invasion, more than half ($N = 13$) were either receiving MOUD as prescriptions that they could purchase at a pharmacy or were provided with take-home dosing ($n = 6$) that allowed them to intermittently attend the clinic for services. Half of the sample subsequently transitioned to a state-funded MOUD clinic within their city or in another location.

**TABLE 1** Type MOUD clinics participants reported attending before February 24, 2022 and immediately after invasion and during data collection.

| City | Before 24 February 2022 | | During data collection | |
|---|---|---|---|---|
| | Private MOUD clinics | State-funded MOUD clinics | Private MOUD clinics | State-funded MOUD clinics |
| Kyiv | 6 | 0 | 1 | 5 |
| Kharkiv* | 7 | 0 | 3 | 4 |
| Poltava | 3 | 0 | 3 | 0 |
| Odesa** | 3 | 1 | 3 | 1 |
| Zaporizhzhia | 1 | 0 | 0 | 1 |

*Four people moved to Lviv and one person moved to Poltava.

**One person attended both types of clinics before and after 24 February 2022.

TABLE 2 Demographic characteristics of study participants (*N* = 20).

| Participant characteristics | N = 20 |
|---|---|
| Sex | |
| Female | 1 |
| Male | 19 |
| Median years | 37 |
| Medication for opioid use disorder (time of interview) | |
| Methadone, oral tablet | 15 |
| Buprenorphine, sublingual tablet | 5 |
| Type of MOUD clinic before 24th February → (during data collection) | |
| State-funded | 0 → (10) |
| Private | 19 → (9) |
| Both | 1 → (1) |
| Form of MOUD receipt before 24th February → (during data collection) | |
| Daily at the MOUD clinic | 1 → (0) |
| Take-home dosing | 6 → (7) |
| By prescription at a pharmacy | 13 → (13) |
| Median years of injection before MOUD initiation, years | 14 |
| Median and duration on MOUD, years | 4 |
| Median medication dosages (mg) before 24th February | |
| Methadone | 134 |
| Buprenorphine | 13 |
| Had their MOUD medication dosage decreased after 24th February | |
| No | 10 |
| Yes | 10 |

Themes of stress and uncertainty were prevalent in the initial days after the full-scale invasion. The navigation of access to MOUD, and perceptions and lived experiences regarding state-funded versus private clinics were central to the participants' experiences.

## 3.2 Double stress and uncertainties

Many participants were caught off-guard by the onset of the full-scale invasion of the Russian army into Ukraine; however, some mentioned concerns before 24 February 2022 about potential closures of their MOUD clinic in the event of military intervention. One participant even inquired about the contingency plans of the MOUD clinic in the case of a full-scale invasion, receiving a response in jest that suggested the clinic would continue its services without interruption.

*I asked them, what will happen when the war starts? - "You will work, won't you?" That's what they say - "We will even deliver to the trenches." They even made jokes.*

Stepan, from Kharkiv, moved to the clinic in Lviv

Participants were further stressed by the memory of the closure of MOUD in the Autonomous Republic (AR) of Crimea shortly after the Russian Federation annexed the peninsula in 2013.

*Well, now, God forbid, so that it doesn't turn out like in Crimea, because I already wanted to go to Germany. Here are the old ones [patients]; they are terribly afraid of this... Because we have already gone through it and know how it is and what it is.*

Oleksandr, from Odesa, changed the clinic in the same city

The abrupt onset of the invasion resulted in participants having varying amounts of medication on hand, sufficient for between 1 and 10 days of take-home dosing. Initially, participants mostly sought information regarding the operational status of their MOUD clinics and attempted to secure medication supplies to last. Experiences varied by city: some participants received confirmation that their clinics would continue operating as usual, alleviating immediate concerns; other clinics distributed the maximum allowable amount of medication available to patients; however, others became unreachable. These three approaches exemplified private MOUD clinics' strategies to navigate through uncertainty: optimistic anticipation, proactive preparation for adverse outcomes, or relinquishment of responsibilities toward their patients.

*Everyone thought that it was temporary. On the day of the full-scale invasion, the clinics were working. Some people thought it was going to be a short scare. In a week, it became apparent that it was for a long time.*

Stepan, from Kharkiv, moved to the clinic in Lviv

Following the initial shock, participants were confronted with decisions emerging from concerns about the continuity of MOUD at their respective clinics and within their cities. They expressed insecurity and confusion regarding the possibility and means of continuing their MOUD treatment.

*I don't understand what's next... I was starting to half the pills... I left Kharkiv. I stayed in one place. I had to wait... Kharkiv, Pesochinka, Kremenchuk, Znamianka, Lviv one place, Lviv another place.*

Mykolai, from Kharkiv, moved to the clinic in Lviv

Participants adopted various approaches depending on whether their respective clinics remained operational, whether staff could continue working, the availability of medication in pharmacies for prescription, and concerns for personal and loved ones' safety. They either continued receiving medication at private MOUD clinics (as observed in Odesa and Poltava), transitioned to governmental clinics within the same city (as in Kyiv), relocated to another city to access private clinics (e.g., participants from Kharkiv moved to Poltava), or switched to governmental clinics in a different city (e.g., Poltava or Lviv). These diverse experiences highlighted the disparate circumstances surrounding MOUD programs nationwide and the healthcare system's response. Furthermore, participants' initial wartime experiences influenced their attitudes toward different MOUD options, either reinforcing preferences or prompting reconsidering of long-term MOUD plans.

*I will stay at the state one [after the war's end]... I am somehow more comfortable here. I don't want to go anywhere.*

Oksana, from Kharkiv, moved to the clinic in Lviv

## 3.3 Access

The theme of access to MOUD medication encompassed the operation of MOUD clinics, staff availability, and the accessibility of medications (methadone and buprenorphine). These critical factors shaped the initial experiences of MOUD patients in the five major cities.

### 3.3.1 MOUD clinic operations

Participants from most cities included in our study experienced disruptions in the operation of private MOUD clinics. Consequently, they either transitioned to another private MOUD clinic—undergoing the entry procedures anew, including paperwork, consultation, and urine tests—or switched to a governmental clinic.

*Initially, I went to a private clinic to make some kind of stock. But, unfortunately, everything was closed everywhere, as if no one ever worked there. I went to a governmental clinic and received mine [MOUD]. At the same time, I was monitoring the situation with private clinics.*

Petro, from Kyiv, changed the clinic in the same city

*There was one more private clinic, which started to work three days after the war had begun. I went as a new patient; again, I went through the whole procedure, consultations with a narcologist, documents, and a test for drugs in the urine.*

Oleksandr, from Odesa, changed the clinic in the same city

Participants also noted various challenges, including the absence of doctors to issue prescriptions and the closure or relocation of private clinics, particularly in Kharkiv, Kyiv, and Odesa. Despite initial uncertainties, when participants could contact their respective private MOUD clinics, most nurses and MOUD doctors were accessible at all clinics.

Disruptions in the operation of private MOUD clinics were not uniform. A participant from Odesa recounted how their private MOUD clinic not only continued its operations, but the staff also provided reassurance regarding the availability of prescriptions. Moreover, the staff strived to adhere to the prescription schedule and initiated processes to provide prescriptions for 30 days, which was allowed by the Ministry of Health. In another city, Zaporizhzhia, a participant described interruptions in the operations of the MOUD clinic and the pharmacy, noting that the clinic opened only 1–2 days per week. When unable to obtain his medication, the participant resorted to purchasing over-the-counter medications from the pharmacy to alleviate withdrawal symptoms. Some participants noted improvements in the conditions of MOUD clinic operations, such as receiving take-home medications for extended periods—up to 30 days.

*Doctors reassured us that there would be no difficulties or troubles. They said adjusting to the higher duration [of medication stock] is necessary, and I'll be able to receive for a month.*

Volodymyr, from Odesa, did not change clinics

*The hospital [MOUD clinic] worked irregularly, once or twice a week. There was a problem with the medication; the pharmacy was closed, did or did not have the drug. Sometimes I was missing my doses. I was taking "Lyrica" to have no withdrawals.*

Andriy, from Zaporizhzhia, changed the clinic in the same city

When participants experienced changing MOUD clinics within the same city, most reported a relatively smooth transition, often receiving medication on the same day. Those who were also internally displaced experienced interruptions and delays in commencing medication at new clinics. While evacuating from Kharkiv, one participant rationed available medication until reaching a new clinic in Lviv. The journey took approximately 4 days, with an additional couple of days required to locate the clinic and secure medication.

*On February 24 I had [medication] for nine days. I understood that no one knew what happens next, so from the first day I started to take half of a pill less. I have left the Kharkiv on a 7th day, the trip took me four days... To stop somewhere was possible only on the 13th day. I managed to take longer what I reduced gradually, but I felt bad, to be honest.*

Stepan, from Kharkiv, moved to the clinic in Lviv

### 3.3.2 Medication

Challenges regarding the availability of MOUD medications were primarily associated with reduced dosages at governmental clinics or the absence of medication in pharmacies. Participants who attended private clinics and obtained MOUD through pharmacy prescriptions encountered significant obstacles, as medicines were frequently unavailable or the pharmacies were closed.

*A few days before the war started, I received a prescription from my private provider and came to the pharmacy to get my buprenorphine. The pharmacy was closed for us - drug users, even though people were working inside and many drug users with prescriptions outside. The territorial defence was not letting us in. I came the following day and the day after and could not buy buprenorphine with my prescription.*

Sergiy, from Kyiv, change the clinic in the same city

Governmental clinics in Kyiv continued operations with available medication; however, due to limited medication availability, doses were capped at a daily maximum of 100 mg of methadone, similar to the situation reported in Odesa. Participants from Poltava described fewer disruptions to clinic operations but observed a change in the type of methadone available (with the methadone produced in Odesa being supplied instead of the one produced in Kharkiv). Furthermore, the availability of methadone in pharmacies varied depending on whether the pharmacies received their methadone supplies from

Kharkiv or Odesa. Some pharmacies ceased selling methadone altogether. At one point, methadone was reportedly available at only one pharmacy in Odesa, albeit without shortages. A participant from Zaporizhzhya indicated that prior to 24 February 2022, only one pharmacy in the city accepted prescriptions from private MOUD clinics, and this pharmacy ceased operations following the initiation of the full-scale invasion.

> *The doctor explained that we have a limit. We cannot take more than 100 mg per 24 h.*
>
> *…*
>
> *…Kharkiv's methadone disappeared, and Odesa's [methadone] was in only one pharmacy in town. Well, from all clinics [people] were going there, and there were enough [medication]. There was no such situation that someone arrived and there was nothing there.*

Volodymyr, from Odesa, did not change clinic

An increase in the duration of take-home dosages or prescriptions was perceived positively but brought unintended financial consequences for patients at private MOUD clinics. These clinics often strongly recommended, or sometimes mandated, 30-day prescriptions, requiring patients to purchase a month's medication in a single transaction. For instance, one private clinic altered its prescription duration policy, establishing a minimum of 20 days while encouraging 30-day prescriptions; this represented a change from previous options, which allowed for 5- or 10-day prescriptions. One participant initially welcomed receiving a 30-day supply from a private MOUD clinic but eventually ran out of funds and transitioned to a governmental MOUD clinic. Another participant, despite continuing with the program, expressed dissatisfaction with the modified prescription duration policy.

> *Initially, I could buy for 5 or 10 days when I entered the clinic. The war began, a small amount of time passed, and the clinic changed this policy, starting to sell for at least 20 days, but preferably for 30.*

Oleksandr, from Odesa, did not change clinics

## 3.4 Preference for state-funded versus private clinics

In addition to the variation of participants' experiences by city, they diverged by whether private MOUD clinics offered take-home doses or prescriptions. These experiences, intertwined with participants' previous preferences for a MOUD modality and their socioeconomic status, either strengthened their inclination toward private MOUD, enhanced the appeal of governmental MOUD clinics, or led to the contemplation of stopping MOUD entirely. According to participant reports, private MOUD clinics that offered take-home doses or actively liaised with pharmacies were better prepared to maintain MOUD provision in the initial phase of the full-scale war. Furthermore, participants felt reassured when private MOUD clinics could relay information about the availability and location of MOUD medications in pharmacies, reinforcing the perception that these private entities are client-focused. Notably, these observations were primarily reported by participants in Poltava, a city comparatively less impacted at the time of data collection.

> *On February 24, I had some supply of methadone at home, but I called my clinic right away asking what is happening, whether they were working, if I could come earlier to pick up additional medication… they assured me they were working regularly, just like before the war.*

Bogdan, from Poltava, did not change the clinic

Participants who opted to continue with private MOUD clinics accepted alterations in clinic operations, including price increases, extensions in the minimum number of days for which a prescription could be provided, and caps on maximum dosing. In our study, participants from Kyiv indicated that post-24 February 2022, only state-funded MOUD clinics remained operational. A majority transitioned from private to state-funded clinics due to the lack of responsiveness from the private MOUD clinics. As a result, those who transitioned to government-run MOUD clinics—amid closures or unresponsiveness of private MOUD clinics or pharmacies that previously filled prescriptions—developed a preference for governmental clinics owing to more reliable medication access. Furthermore, participants regarded governmental MOUD clinics as more dependable and sustainable amid the conflict due to their perceived obligation to citizens. In contrast, private clinics were viewed as commercial entities susceptible to abrupt closure and bearing no responsibilities toward citizens.

> *I would choose a governmental clinic over a private. Why? First of all, it looked more reliable once the war broke in. It is more sustainable and seems to have certain responsibilities for its patients. And private – this is just business, just money, and business can shut down anytime.*

Petro, from Kyiv changed the clinic in the same city

Simultaneously, other participants expressed concerns that governmental MOUD clinics might face closure, akin to the discontinuation of MOUD experienced by hundreds in the AR Crimea in 2014. Such concerns led some individuals to contemplate ceasing MOUD entirely as a strategy to navigate the uncertainty surrounding MOUD in the event of occupation.

> *I am planning to gradually taper off OAT [MOUD] if possible, maybe by 5 mg…I do not want to depend on it, on the system… What if the program closes?*

Stepan, from Kharkiv, moved to the clinic in Lviv

## 4 Discussion

This study analyzed the lived experiences of individuals undergoing MOUD treatment at private clinics in Ukraine within the initial months following the full-scale invasion by the Russian Federation. It provided new insights into the interplay between the stress and unpredictability characteristics of the invasion's early days, the experiences associated with accessing MOUD, the varied responses from MOUD private clinics, and the precarious circumstances in which individuals found themselves. These

experiences either strengthened or altered preferences toward the private MOUD modality. Some reports suggest that challenges persisted for individuals who evacuated outside Ukraine (21).

Two predominant MOUD clinic options, which operate independently, have been described in Ukraine: the state-affiliated MOUD program, which was implemented and overseen through a network of state-funded healthcare facilities, and the less explored option of private MOUD programs, which were fee-based and operated by private clinicians who worked closely with pharmacies (15, 25). The principal distinctions between these options lie in the payment structure for services provided and their visibility and reporting to state authorities. Private MOUD programs allow participants to remain unregistered (13) and largely undocumented by healthcare or other governmental authorities (15, 25).

The variable experiences reported by clients at different locations and certain private MOUD clinics suggested that the private MOUD sector in Ukraine is not homogeneous in its operations, resilience capacity, guiding principles, or the challenges posed by the unique circumstances arising from the full-scale invasion. These disparities in experiences and operational models offered valuable insights that can significantly contribute to discerning the effects of shock on privately run essential health services. Using the results of this study, researchers and policymakers can derive an understanding and perspectives that can inform and enhance approaches to handling crises in future. Appreciating how different MOUD service delivery models respond to and operate under crisis conditions is crucial for developing robust, resilient, and effective SUD treatment systems that absorb and adapt to crises.

Health system responses to acute conflict are time- and context-specific (33). Within our study, the identified theme of access—derived from experiences around the functioning of MOUD clinics, staff availability, and the accessibility of MOUD medications—was also a principal focus of governmental oversight (14, 15, 20).

During the initial months of warfare, the national MOUD hotline witnessed a 3-fold increase in calls, and a third of these inquiries originated from MOUD patients who had previously obtained their medications from private MOUD clinics, seeking information on enrollment in governmental programs (34). Our results underscored that securing sustained access to MOUD among patients at private clinics emerged as a paramount concern across various cities. Governmental and partner initiatives aimed at providing and coordinating vital information for MOUD patients were implemented, employing various channels, including chatbots, official websites, and direct communication at MOUD clinics (14, 15, 34). This streamlined communication strategy likely guided some patients at private MOUD clinics, aiding their decision-making on whether to transition to different clinics within their cities or to relocate altogether. Experiences reported by participants still varied based on the city and its proximity to conflict, ranging from private MOUD clinics actively providing information and assurance regarding the continuation of operations to others displaying non-responsiveness or complete shutdown of facilities. Earlier reports also highlighted the capability of certain private MOUD clinics to collaborate effectively among themselves and their governmental counterparts to ensure the continuity of MOUD (30). This further underscored the importance of swift, coordinated, and effective communication responses at all levels to preserve access to crucial healthcare services amidst the challenges posed by crises and displacement.

When some private MOUD clinics ceased operations altogether, governmental clinics demonstrated resilience and adaptability, enrolling more patients and maintaining medication dispensation by introducing capped maximum dosing. This response was reported through the triangulation of surveillance data, reporting mechanisms, and surveys targeting patients and providers (15).

Legislative amendments were pivotal in sustaining MOUD provision for individuals with SUD at state-funded facilities, as documented in governmental and international agency reports and peer-reviewed studies (14, 15, 20). These alterations included the authorization of MOUD take-home dosages for up to 30 days, the permission for healthcare facilities operating under martial law to store a 3-month supply of medication, the regulation of MOUD distribution to regions with critical MOUD needs, and the establishment of mechanisms enabling regions and healthcare facilities to request necessary medication amounts. These adjustments, based on the needs of internally displaced persons rather than existing schedules, exemplified the health system's adaptive response to the crisis. These efforts also assured access to MOUD during the transition between clinics for many of our participants.

Some efforts also positively impacted private MOUD clinics, notably regarding take-home dosing and 30-day prescriptions and the supply of MOUD medication to areas with low stocks. The 30-day take-home dosing policy, however, had unintended consequences when private MOUD clinics prioritized this option, leading to financial constraints for some participants.

These findings provide valuable insights into the importance of agile policy responses and legislative adjustments amidst such crises, emphasizing the importance of considering the needs of MOUD patients regardless of the type of clinic where people receive services. The absence of such policies may lead to discontinuity of care, which some recall from tragic outcomes in AR Crimea, where disruptions led to overdose, suicide, an increased risk of HIV, and death (10). It highlights the need for flexibility in policy implementation to accommodate the needs of displaced individuals while also bringing attention to the unintended consequences that policy changes may have on patients.

Our study's key finding, despite variations in individual experiences by specific MOUD clinics and different city contexts, is that participants predominantly managed to continue their MOUD following the initial shock and uncertainty engendered by the onset of the invasion. This continuity in MOUD is likely attributed to the health system's and individuals' resilience and adaptive capacity. The health system responded through strategic legislative and logistical initiatives by stakeholders and effective coordination, and individuals were remarkably resilient and able to navigate the complexity of a rapidly changing environment. As the war persists, especially with barrages of missiles and assaults across the country and remote from occupied territories, people with substance use disorders are increasingly vulnerable to stress (35, 36), which was observed as harm reduction services were disrupted by the war, making it crucial for both private and state-funded MOUD clinics to screen for and treat comorbid psychiatric and substance use disorders. These indicate the necessary next steps in service delivery adjustments to maintain individual and public health.

Despite the many important findings, this study is not without limitations. First, this qualitative research, employing rapid data collection and analysis, sought to offer insights into the lived experiences, priorities, preferences, and behaviors of MOUD patients at

private clinics during the initial phase following the initiation of a full-scale invasion by the Russian Federation. These insights may be useful in documenting, systematizing, informing policy, interventions, and communication strategies. Nevertheless, these data cannot reflect the experience of patients with other services and health system responses nor the full variability of experiences of MOUD patients at private clinics in Ukraine, especially since we did not interview MOUD patients who were unsuccessful in continuing their treatment. We included efforts to conduct targeted sampling across different cities and continued interviews until saturation (at which no additional unique insights emerged) was achieved, followed by rigorous analysis. Individuals who were successful in navigating the challenging MOUD terrain, however, were more willing to share their experiences—possibly with less urgent, pressing concerns—might have been more inclined to participate in this study. While the experiences of individuals receiving MOUD treatment from private facilities during a significant crisis are scant in existing literature, it is imperative to acknowledge that these accounts may not fully capture the experiences of individuals in occupied territories or regions engaged in active combat. Second, online interviews without video have limitations compared to the often-preferred face-to-face format, though ample literature supports such approaches, especially during the recent COVID-19 pandemic (37, 38). Data collectors during such interviews may struggle to foster a trusting and comfortable atmosphere due to the absence of non-verbal cues and direct personal interaction. These factors could potentially impede the development of rapport between the interviewer and the participant. Nonetheless, during a full-scale invasion and significant mass displacement, utilizing these interviews represented the most pragmatic and feasible methodology available, as it was minimally disruptive and non-threatening for participants. It was also safer for patients and interviewers, overcame geographic constraints during the war, and allowed participants more anonymity. Crucially, a qualified and proficient team member who has accumulated experience conducting online interviews since the onset of the COVID-19 pandemic administered the interviews. Given the context, the benefits of employing online interviews significantly counterbalance the inherent limitations of this data collection mode. Third, we collected data in the early months of a full-scale invasion, thus not capturing the long-term experiences of MOUD patients. This limitation presents a research opportunity to explore the trajectories of this vulnerable population in a protracted crisis. Fourth, the mode of data collection constrained the depth of exploration for various topics, leaving some pertinent aspects of the experiences insufficiently examined. Future research endeavors may benefit from probing how stress and uncertainty during crises might drive individuals to utilize non-prescribed opioids and other illicit substances. It is also vital to scrutinize the strategies individuals deploy to navigate stress and uncertainty during emergencies and understand the availability and efficacy of formal and informal crisis intervention mechanisms accessible to individuals in these periods.

This study enriches the existing body of knowledge regarding the experience of substantial crises that disrupt essential public health and healthcare services, offering insights that bear global relevance. It underscores managing uncertainty and access as pivotal elements of health system resilience, applicable to both the public and private sectors. Moreover, the accounts provided by our participants corroborate previous reports (14, 15, 20), illustrating the concerted efforts by stakeholders at various levels to mitigate the disruption wrought by the war on MOUD delivery. These findings offer valuable lessons for international audiences, highlighting adaptive strategies and responses integral to sustaining critical healthcare services amidst crises.

## Data availability statement

The datasets presented in this article are not readily available because the dataset consists of audio records of online interviews with patients receiving MOUD. We opt not to make this dataset available to protect the confidentiality of participants. Upon request, however, we may provide summaries of analytic categories and transcripts (but not audio-recordings themselves). Requests to access the datasets should be directed to hmazhnaya@gmail.com.

## Ethics statement

This study was reviewed and approved by the Institutional Review Boards at the Ukrainian Institute on Public Health Policy (Submission id 2019-009-04). The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because the data collection was conducted through online interviews, written informed consent would have been the only document identifying our subjects.

## Author contributions

AlM: conceptualization, methodology, formal analysis, validation, data curation, writing – original draft, and writing – review and editing. AnM: project administration, resources, writing – review and editing, and supervision. IP: project administration, and writing – review and editing. FA: writing – review and editing, supervision, and funding acquisition. All authors contributed to the article and approved the submitted version.

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# Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The handling editor JR declared a shared affiliation with the author FA at the time of review.

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# Re-examining provider perceptions of best pre-war practices: what elements can help opiate agonist therapy programs in Ukraine successfully survive the crisis?

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**Purpose:** This paper seeks to explore and understand what constitutes successful opioid agonist therapy (OAT) programs from the views of Ukrainian OAT providers in their context-specific accounts. Prior to the ongoing war the Ukrainian addiction treatment system made great strides to expand its OAT program and increase the number of patients. Since the beginning of the war there has been much alarm that those hard-earned successes will be destroyed. However, emerging evidence suggests that the Ukrainian OAT programs have shown signs of resilience in the face of adversity albeit at great cost. What aspects of the OAT programs developed prior to the crisis have been helpful to allow them to weather the storm? Using the data from 24 addiction treatment providers, this paper describes the essential elements of the OAT programs that preceded the current crisis which made them robust over time. By examining the narratives of the participants interviewed pre-war and pre-COVID-19 the paper reveals structural and cultural elements of the OAT programs before the perfect storm that are likely to endure. To the best of our knowledge, no one else has investigated OAT providers perspectives in Ukraine prior to the crisis which makes this paper extremely salient to understand both the robustness and the vulnerability of MAT programs in Ukraine during the war and going forward.

**Methodology:** The data come from qualitative semi-structured interviews with 24 OAT providers throughout 5 regions of Ukraine. Participants included front-line clinicians, head narcologists, and chief doctors from TB clinics, district hospitals and drug addiction centers. Using a coding scheme of 103 inductively developed categories we explored participants' perceptions of their OAT program.

**Findings:** In the stories shared by clinicians pre crisis, three major interconnected themes focused on economic uncertainty at the institutional level (leading to under-staffing), structural capacity of the program, and clinicians' professional identity, shaping differing views on application of rules for administrative discharge, take-home dosing, and the potential for scale-up. Knowing the data collection was completely unbiased to the current crisis, interpreting the findings helps us understand that OAT clinicians have had "years" of training under conditions of duress in Ukraine to overcome barriers, find creative solutions and form a support network that became indispensable in surviving the current humanitarian catastrophe.

**Conclusion:** In the discussion we point out that the current crisis magnified the pre-existing challenges as the providers approach toward overcoming them was

already largely present before the crisis (just on a different scale). The underlying fragility of resources was a constant since OAT inception in Ukraine. Historically, providers in Ukraine operated in a system that was under-funded in the absence of solid governmental funding for OAT programs, yet they came up with solutions which required ingenuity that they took pride in. This gives hope that addiction treatment in Ukraine and OAT programs will not be casualties of this humanitarian crisis and providers and their patients will persevere.

# Introduction

The Covid-19 pandemic shut-down coupled with the Russian invasion in Ukraine that began on February 24, 2022, constituted the sudden crisis, whose one-two punch impact was felt on many levels in Ukraine. One documented impact was the risk of abrupt interruption of medication and OAT service delivery to 17,232 people on OAT at the beginning of the invasion. Russia's attack on Ukraine resulted in displacement of approximately one-third of the population. Displacement had an immediate impact on OAT patients who relied on local pharmacies and OAT programs for daily dosing (1). In a desperate attempt to minimize the abrupt interruption of medication, OAT providers sent Telegram-SMS messages to patients offering to meet them in designated areas to personally deliver take-home doses.

The documented reaction of the Ukrainian OAT services to the impact after Russia's 2022 invasion was the relocation of OAT programs to the western region of Ukraine. OAT providers continued to share information with each other via Telegram-SMS to minimize the loss of patients and to continue care and medication assistance. In stark contrast to pre-crisis policy, OAT providers allowed take-home doses (10- to 30-day supply) as local pharmacies access to emergency medication was disrupted.

While inspiring to emergently look for solutions, the crisis exposes and amplifies pre-existing deficiencies as well as strengths. This paper aims to describe the status quo in the addiction treatment system in Ukraine and its relative strengths and weaknesses before the dual crisis hit. This is significant to unpack the characteristics of the addiction treatment system and the experiences of the addiction treatment providers pre-crisis to understand what issues pre-dated the crisis and with which the facilities and staff were already familiar and to which they have developed robust responses. Likewise, looking at the addiction treatment system pre-crisis when there was no major disruption can help us explain why certain challenges were subsequently bigger than others and what helped the facilities and the staff to survive.

To understand what was at the heart of the status quo prior to crisis will ultimately help to build a viable post-crisis strategy for addiction treatment in Ukraine and elsewhere. And in so doing, the point of view

of providers is key, but coincidentally has been largely overlooked, making analysis of addiction treatment providers' accounts in Ukraine using exclusive data obtained pre-crisis distinctive and extremely salient.

When we started researching this topic 4 years ago, we found only 3 publications in the literature focused on testimonies of Ukrainian addiction treatment providers themselves (2–4). Now there are only 5 publications (1, 5) signifying that all through COVID all the attention was placed on patients and service users, but little attention has been paid to this provider group and that is why this data is so significant. Considering how important it is, there was very little attention paid.

This article presents findings from the analysis of data collected in 2017 from OAT providers to understand barriers and facilitators of the success of the OAT system in Ukraine (and never yet published). The data was collected during the pre-crisis time and looking at findings from the vantage point of the present time sheds light on how these barriers underlie the subsequent risks and how facilitators helped to offset them especially during the war and humanitarian crisis.

This article highlights healthcare staff's rarely heard perspective on the challenges that pre-dated crisis in the Ukrainian addiction treatment system. It reflects on whether having learned how to navigate these challenges over the years gave buttressing against the crisis to the addiction care providers, allowing them to lean on well-practiced skills. But where is the boundary? At what point does it break? What is the call-for-action from this knowledge? This article contributes to finding the answer to this question.

Interestingly, before the crisis, addiction treatment providers drew their wish lists including their recommendations that in their view would improve the addiction care system. These wish lists also revealed the fundamental limitations and deficiencies of the system that the crisis had laid bare. Although these recommendations are made in real-time, they existed pre-crisis but were ignored by the governmental officials and policymakers.

The problems pre-date the crisis and providers concerns must be taken seriously because it appears that what they have identified over the years are indeed the issues of the system. The wish list is like an "evidence-based time capsule." Although now the call for action is not much different than what providers asked for years ago, it is now of greater significance, and the voices of addiction treatment providers need to be heard now more than ever as a group with specific needs and challenges. It is increasingly appreciated that during the crisis like Covid-19 and the war, providers are at risk for burnout despite (or perhaps because of) being flexible, creative, resilient in coping with challenges and

finding new ways to help everyone but not receiving much support themselves. Healthcare is an essential societal system, and the providers were used to being altruistic and professionally proud to deal with the ongoing issues. Due to the existing challenges the nature of the system pushed providers to their limits daily. Providers burnout was noticed in healthcare systems worldwide after COVID shown by the shortage of nurses and front-line clinicians (6–9). Throughout COVID data came from multiple places that providers developed the biggest mental health impact in terms of anxiety and became the most affected group in comparison to other groups (10–16).

In sum, this article takes the readers back to the pre-Covid-19 Ukraine to find solutions to today's challenges and to see what the learnings from the past can teach us in dealing with the aftermath of humanitarian crisis today. First, it describes the setting of addiction treatment in Ukraine, then presents findings from the original qualitative study of addiction treatment providers and interprets learnings from these findings from the contemporary vantage point.

## Setting

## The overview of OAT programs in Ukraine

To understand providers' accounts in the Ukrainian context before the Covid-19 and the war stroke, we gathered information from policy documents of the Ukrainian Government, from experts at the Ukrainian Alliance for Public Health (i.e., Alliance), and other non-governmental organizations (NGO) reports.

### Establishment of OAT programs in Ukraine

Ukraine is a LMIC with a population of approximately 42 million. At the time of data collection, it was estimated that there were 340,000 PWID, mostly of opioids, 4.5% of whom were enrolled in OAT programs throughout various regions of Ukraine. Yet, to curb HIV and HCV transmission, the World Health Organization (WHO) recommended that at least 20 percent of the estimated number of PWID receive OAT (17).

Opioid Agonist Therapy (OAT), in the form of buprenorphine tablet, was introduced as a pilot in 2003 by the Global Fund for HIV+ harm reduction clients (18, 19). Once it proved to be successful, the program was expanded countrywide in 2004. A pilot methadone program was started subsequently, and by 2008 MAT included both buprenorphine and methadone. By the end of 2021 only 10% to 15% of all OAT patients in Ukraine received buprenorphine as methadone is cheaper ($4 vs. $12 per patient per month) (20–22).

Historically OAT programs started in high priority areas such as Kiev, Dnipro, Odessa, and Mykolaiv where drug use and HIV were more prevalent to address the HIV-tuberculosis (TB) crisis. The first sites, funded by Alliance and The Clinton Foundation, were integrated into existing drug addiction clinics, TB clinics, and city AIDS centers. The Ministry of Health (MoH) regulations for OAT sites were based on experience of other countries, and some local knowledge from the Ukrainian stakeholders. The regulations were developed on evidence-based practices for addiction treatment and were carefully thought through and controlled throughout the country, with very careful measured implementation, and the measures of control were based on social dialogue among various stakeholders and some consensus that

was built. The development was not fast and took its time and every step of the way was done thoughtfully and cautiously.

The first sites were located on the outskirts of cities where TB hospitals, AIDS centers, and addiction clinics were located. Eventually, new sites were opened throughout the cities (19). Since 2018, some OAT programs were integrated into primary care medical facilities.

According to communication with Alliance at the time of the study, there were approximately 947 narcologists across 211 OAT program sites and 11,385 patients (or 3.3% of the estimated population of PWID) were enrolled throughout Ukraine (23). Sites varied size-wise between 6 and 300 patients, and some had waiting lists while others had patient vacancies. The MoH (Center for Public Health) determined the number of treatment slots for each region.

The regulatory framework for OAT provision in Ukraine includes the federal (i.e., national) law #693 in effect since 1991. This law mandates that all patients receiving treatment for addiction are registered in the national drug user's database. Studies showed this is the biggest disincentive to new patient OAT access as employers and governmental departments check this database before employing a person or issuing a driver's license (3, 18). De-implementation of employment or driving restrictions for OAT patients were advocated, but changes were slow. The second regulatory element is the Order 200 passed in 2003 and revised in 2015 to allow take-home dosing to OAT patients who meet certain conditions.

## Methods

The senior author collected the data in 2017 and the first author conducted data analysis in 2018–19, as part of her dissertation project [unpublished]. As the crisis began to evolve, we returned to the analysis and reconsidered its findings for insights that can help to understand the processes in the addiction treatment system of Ukraine in response to the crisis, as they are currently evolving. Knowing the data collection was completely unbiased to the current crisis, upon re-examination, certain points appear to be very sharp given the light we can now shine on them.

## Participants

The data came from 24 qualitative (semi-structured) interviews conducted in February 2017. The interview participants included front line clinicians of OAT programs, doctors running OAT programs and senior clinical directors in equal proportions. Every effort was made to ensure the diversity of the sampled participants in terms of the mix of these seniority/roles in each region and across the regions. Five geographic regions were chosen based on their diverse location as well as OAT situation and randomized the providers from there. Recruitment was conducted through professional networks of OAT providers in Ukraine with whom we have been working with since 2015.

One way where a qualitative approach is most powerful is in a circumstance like this, where very little to nothing is known about the circumstances of the group in question (i.e., OAT providers in Ukraine) and formative work needs to be done to learn and *understand* their context-specific accounts and from these individual accounts, build a rigorous collective story, in which other OAT providers (in

Ukraine but also possibly elsewhere) may recognize themselves and their experiences.

## Instrument

The purpose of the interview was to capture the experience of providers working at and running the OAT program in Ukraine. The interviews included conversations about what types of challenges they faced in running these programs and how they resolved or coped with these challenges. Importantly we received feedback on what aspects they were particularly satisfied with. During the interview process we kept a keen ear open for details on barriers and facilitators given the push to scale-up the program in the near future. The data came from 24 qualitative interviews conducted in February 2017 using an interview guide (Appendix B) with clinicians from the OST programs in Ukraine. Please see Table 1 (Appendix A) which outlines a list of participant attributes. As previously mentioned, in order to capture diversity, participants were ~ equally recruited from five different regions in Ukraine (so that about the same number of participants are from each region). Approximately 1/3 of participants were front-line clinicians in the OST programs (junior doctors, nurses). Approximately 1/3 of participants were doctors running the OST programs. The remaining ~1/3 of participants were senior doctors who held senior leadership positions in their respective hospitals/ organizations (e.g., Head of the regional AIDS Center) and who oversaw the OST program as part of their job's mandate. Every effort was made to ensure the diversity of the sampled participants in terms of the mix of these seniority/roles in each region and across the regions. Five geographic regions were chosen based on their diverse location as well as OST situation and randomized the providers from there.

Recruitment of participants was facilitated by the Ukrainian Alliance for Public Health, an organization that has strong networks and good relations with addiction treatment clinics across Ukraine. Each interview was 20–25 pages in length, lasted from 35 to 60 min and was conducted in person by the last author in the language of the participant's choice – either Russian or Ukrainian. Interviews were transcribed verbatim and translated into English by qualified translators, the quality of the translations were verified by the second and the senior authors who are native speakers. Interviews were anonymized for protecting participants' confidentiality; identifying information such as names of clinics or names of participants is not disclosed.

## Analysis

We utilized Dedoose (version 8.1) software (2018), a cross-platform app for analyzing qualitative and mixed methods research to manage the data. The first step in the analysis involved the task of reading and coding each excerpt into a coding tree where it can then be further analyzed to better understand the experiences of running an OAT program in Ukraine.

To develop the coding tree, parent codes were created. A parent or root code is a more general description of topics that are discussed in the interviews. Child codes were then added where necessary. A child code is a subordinate of the parent code and is a more specific

sub-topic that is discussed within topics. For example, one of the parent codes is "barriers" and the child codes are "procurement," "social barriers," and "structural barriers."

The process of creating the codes was inductive as all of the members of the team read a sample of the interviews. We then had two rounds of discussion to formulate the core codes for categorization and create the coding tree in Dedoose. Once the core of the coding tree was set, we focused on creating the subordinate or child codes, we then re-read the interviews and categorized each excerpt into the appropriate code on the tree. Some excerpts could be cross-coded into two categories depending on their topic of discussion. For example, if a patient was previously discharged for diversion and was then allowed to re-enter the program the excerpt would be coded under the parent code "*clinical challenges* (sub-code: *diversion*)" as well as the parent code "*OST programmatic structure* (sub-code: *administrative discharge*)" and parent code "*rules for access* (sub-code: *return to OST*)". Using a coding scheme of 103 inductively developed categories we explored participants' perceptions of the program. These categories were aggregated into 15 parent codes which in turn were aggregated into three broader interconnected themes.

## Results

Analysis of the data from the interviews with OAT providers revealed three themes on how they understand what shapes success of an OAT program: legal and economic underpinnings of OAT provision, program's organizational structure, and professional identity of providers. Economic policies challenged quality of care by uncertainty in program funding, inadequate staffing, and challenges surrounding treatment scale-up. Programmatic structure challenged success by limiting patient capacity, and difficulties around inter-site collaboration that hindered coordination of care. Yet success was supported by a sense of professional pride in patient achievements, being recognized as an expert, and being included in decision-making.

Three major interconnected themes focused around:

1) **Economic uncertainty at the institutional level (leading to under-staffing)**

Providers were aware that economic sustainability of the program and its ability to endure overtime, provide jobs to clinicians, and medication to patients depended on macro policies of Ukrainian government or international institutions like the Global Fund. In the following excerpt, an OAT provider shared their perception of economic uncertainty for their program as the Global Fund was expected to offload greater responsibility for funding the programs to the Ukrainian government (and providers were unsure if the government was up to that challenge). Concerns included the supply of medication and insufficient clarity of policies for procuring it.

[Provider 13: "*This incompleteness of this part of chain to supply the patient with drugs and the same with the addiction inpatient care. Now, the Global Fund will end, where should we buy; what prices/ agreement?…we do not have such experience*"].

Providers' accounts stated OAT programs were understaffed, and already exceeded capacity causing reluctance to admit more patients without further resources (being paid more, being promoted, or hiring more staff). According to communication with Alliance, the average

monthly salary of a front-line nurse and even a doctor was very modest (the equivalent of $200 USD for nurses and $400 USD for doctors).

The status quo before the crisis meant under-resourced as far as staffing is concerned. The provider commentary below describes shortage of staff to provide care to the large patient body.

[Provider 18: *"R: Well, talking about narcological hospital, the staff specifically consists of 198 persons, so it is not enough. We have 15,000 patients registered here but they include not only patients with drug addiction, but also alcohol addiction, about 2,400 patients have drug problems. We have 765 patients on substitution therapy in oblast at 13 sites, and we have 226 receiving Methadone, and 61 receiving Buprenorphine. This is the distribution; they have one doctor and four nurses on staff."*]

The quote from the provider below points out that there may be gaps at the organizational level regarding provisions for compensation (extra compensation) to clinical staff that provide OAT in addition to their general work mandate. OAT providers recognize these gaps and feel concern, dissatisfaction, and anxiety.

[Provider 18: *"medical staff work at narcologist office. The substitution therapy created the extra workload for them, and they wanted to receive some financial support for that. If the manager of the health care facility at raion does not find the resources for extra money, then there is tension."*]

The excerpt below talks about motivation that is both economic but also intrinsic, as clinicians love their job. Yet there is concern that lack of economic remuneration and unclear priorities within the program structure, excessive work burden, and burnout, lead to staff turnover.

[Provider 14: *"The workload is huge; no one released us from our principal work, now this work has to be principal, but here in my unit, the principal job is OAT, this cannot go one without another. They go together. Here we need a lot of motivation, and we of course have those who do not stay for long."*]

The next provider quote echoes the same sentiment in their account, when asked.

[Provider 18: I: *"And do you have high turnover in personnel and patients?"* R: *"…the retention in the program indicators were not so good. But when we could arrange more stable personnel in the staff, the patient adherence became better."*]

Meeting operational needs with adequate staffing has a direct impact on the functional framework of the program as well as on improved patient adherence. Consistency among staff provides job satisfaction to providers and increased stability and structure to patients, whose good outcomes in turn motivate clinicians to continue working.

2) **Structural capacity of the program**

Is bigger better? Does success equate to more patients and/or staff? Providers were sure of one thing: being over capacity was a recipe for failure. There has been continuing pressure by the Ministry of Health on providers to scale up their programs while not increasing their resources and their staff. In providers' view, the size of the program was shaped by the programmatic and institutional level regarding how much medication was procured and how many staff positions the clinic could fill given its public funding. Thus, the program's potential for growth determined which patients are prioritized if only scarce slots are available.

The following two quotes raise the issue of whether retention may be the absolute goal or whether, some patients were better to be let go, for the program as a whole? Providers struggled to find consensus between meeting general administrative rules and requirements and acting in the best interests of individual patients.

[Provider 4: *"We have had, and we keep getting patients who quit the therapy. The reasons why our patients quit the program is … mainly because they either die or get arrested."*]

[Provider 10: *"There are no patients who drop out (unless they get ill); it's about 1–2%. Mainly all patients who were enrolled stay in care for no less than six months; some of them have been here for years."*]

In the pre-crisis status quo, a range of styles existed in which facilities and programs were run. Some were more rigid and took the guidelines literally while others were more relaxed and creative in interpreting the guidelines. Here are two examples of very different approaches.

[Provider 13: 'This is one case when there was an attempt to remove Methadone from the site and we expelled the patient from the program and kept out for 6 months, then we wrote her the conditions for staying in the program and now, thank God, she comes at a certain time, strictly observing all the rules of staying on the site."]

[Provider 20: *"We have not done administrative discharge for as long as 5 years."*]

The pre-crisis status quo included the realization that things were not perfect; there were grievances and wishes that things could be better. Some expressed concerns that without better resources it would be impossible to improve the quality of care; all the while the MAT programs were somehow persevering. Providers wish lists included keeping the workload of clinicians manageable by increasing the number of sites and clinicians so that they can provide care at the appropriate standard.

During the interviews, providers were asked to share what changes they would welcome to increase efficiency. Here is what providers put on their "wish-list."

[Provider 11: *"increase a number of [OAT] sites to make sure that this type of support would be better accessible to anyone who wants to receive it. …there are still certain limitations of how many patients may be enrolled and there are still lines and waiting periods. Plus, it is very difficult to negotiate transition of patients when they travel during the summer…to make sure they are provided with medication at their travel destination. Our partners always respond by saying that they have too many such requests and they simply cannot accommodate all of them."*]

Many of the wishes for what the providers would like to see happen differently, could address the challenges mentioned previously – e.g. diversity of sites can make it potentially easier to cater to diverse challenges of patients.

[Excerpt from interview 23: *"I would like to see the increase in the number of the sites because we have many patients that come to us from different places of Kyiv region because they do not have any sites of this kind closer to their hometowns. That's why they come here. …there should be more sites like this out there as many of the patients say that these sites are their salvation."*]

If scale-up were to occur, the division of labor and job description would continue to be a concern on the organizational level. The following quote expresses concern that providers will have less time to treat patients and suggests that staff scale-up should occur simultaneously with patient scale-up and should be implemented at the policy level.

[Excerpt interview 17: *"There is one rather unresolved issue related to this idea of project scale up. And the issue is this – am I supposed to, as a doctor, fill out detailed information for each patient or can this be done by someone else? Resolution of this simple issue would greatly help us to move on further in our work."*]

The staffing was the function of the funding for the programs, which was decided by policies – either Global Fund or the Government had to clearly put aside a certain budget for the staff. This did not come from the local clinic/organization budget – at least, not at the time of the study. A common theme was that a successful program – in the staff's mind – was one that gave them a continuous job. Thus, economic stability of the program was one such universal issue. This was associated with OAT providers' expectations for whether their jobs and employment would endure, but it also was connected to the OAT providers' wish to have the mark they felt they made on addiction treatment in Ukraine, to endure too. Accordingly, the third key theme is that of professional identity and pride.

   3) **Labor of love: Clinicians' professional pride (and individual level of authority)**

   The findings present providers' individual-level experiences, that embraced their feelings of professional pride and ways in which they experienced and wielded their decision-making authority in their work. There is a range of levels at which the success can be understood and experienced from the point of view of clinicians. It can be understood from the clinical outcomes of patients, and also can be understood by providers having professional pride and satisfaction in the quality of care they provide to patients, the reputation their program and leadership has in the region and throughout the country. Professional recognition for achieving successful patient outcomes was important to clinicians feeling effective in their fields.

[Provider 16: *"Well, who comes to our clinic, the doctors do not go anywhere because (name of head clinician) has created the conditions for work, you should understand, it is very important when you go to work and know that you will be heard, you will be understood, you will get help finally. That's why the staff of doctors are very stable."*]

Is a successful program one where the clinician is professionally successful? Clinicians want to feel recognized as experts in their field by peers from other clinics and regions. They appreciate being consulted and want to consult others.

[Excerpt interview 16: *"That's why we collaborate very closely. If our patients need consultations, we start with our specialists. Yes, all doctors have the highest ranks, and they know peculiarities of the patients with addiction. It is our specialization."*]

As the participant explained below, being recognized as a leader in their field was very valuable and important for them, especially as this recognition came from both domestic and international colleagues. From this point of view, a successful program was one that was recognized as such by global peers in the field of addiction treatment.

[Excerpt interview 16: *"I was the only one out of our specialists that received this certificate of leader in Ukraine. The American colleagues recognized the services of narcological clinic as the best and handed me this certificate. We are really the best."*]

There are different kinds of clinicians (some frontline distributors such as narcologists and nurses where OAT is their only job), and then there are some senior clinicians who are like medical directors of large hospitals who have a portfolio of many departments to oversee, and this (inpatient) drug treatment program is only one of them. The excerpt below illustrates an account from a provider who was at a more senior level. He directed the inpatient drug program under the auspices of the hospital and was less connected therefore was less concerned than the frontline clinicians, as his job was not as affected as the site narcologists and nurses. To this participant, success in terms of his own profession, had a broader meaning, and stemmed from doing well in the management of the large healthcare organization, of which the OAT site was a part. His reference to "global" suggests that he emphasizes the importance of his role and of how well he performs it, for the overall performance of the large healthcare organization.

[Excerpt interview 22: *"The most inclusive definition of my responsibilities is making sure that the hospital remains functional and constantly developing. This includes the guidance related to global level policy, global level hospital management, and global personnel issues. I assign people for the positions of deputy chief physicians, for the positions of the department heads. I am also responsible for hiring physicians of this hospital. The head of HR may search the candidates, but every physician has to have an interview with me to be hired. I am directly responsible for implementation of the city program for HIV infection and also city policies development regarding HIV."*]

Some clinicians were proud of their patient's achievements (making family members happy) and others see it as an award for themselves (giving them more authority, having influence on decisions in the medical system).

Although take-away medication and prescription privileges are allowed state-wide under Order 200, the program is not offered at every site and is at the discretion of the narcologist. Currently, more than 1/3 of patients across the country receive some form of

prescription/take home medication. The change in Order 200 in late 2015 that authorized prescription/take home medication was a game changer for Ukraine, and largely due to the work of ExMAT (3). There are some locations where the site narcologist will not allow these privileges and want every patient to come to the site every day. They will not dispense medication any other way. The large site at the Kiev City AIDS Center is among the sites that do not allow their patients to receive take-away dosing or prescription privileges. The narcologists and the administration of the medical facility at whose premises the OAT site is located decide on this for each individual site. The administration role is equivalent to that of a medical director in U.S. practice.

The three main criteria for new patient admission into an OAT program are registration into the federal law 693 database, having 2 failed attempts to stop using illicit drugs documented in the medical record, and proof of opioid addiction. Registry into the federal database is not a modifiable rule though there is a growing private market that provides long term "detox" using OAT without registering people. Some rules, however, are modifiable at the organizational level of individual OAT sites (at the discretion of the individual site narcologist). For example, some site narcologists will be flexible about the 2 documented failed attempts. Some will go so far as to keep the client in the inpatient clinic for 2 days and document it as 2 failed attempts.

Additionally, some site narcologists will relax the rules of proving opioid addiction by having the patient show up in the morning, perform all of the necessary tests and give the medication on the same day. In stark contrast however, some site narcologists will keep the client at an inpatient clinic for 6 days and observe their withdrawal symptoms to prove their true opioid addiction. Having two failed attempts and proving opioid addiction is a requirement of Order 200.

According to personal communication with the Alliance experts (February 27, 2019), there is a variation in application of discharge rules among the individual sites and it is determined at the narcologist's discretion. Some sites do not administratively discharge patients therefore the only retention loss experienced (outside of patients' voluntarily discontinuing treatment) is when a patient either dies or goes to jail. As an alternative to discharge, if a patient presents with a urine test that is positive for opioids, the narcologist will work with them to slightly increase their dosage to a comfortable level to deter them from using illicit drugs. Contrastingly, some sites will discharge a patient for a urine test that shows positive for cannabis. In sum, even though the system of OAT provision in Ukraine is heavily regulated at the national-level and is based on strict surveillance policy principles that must be observed at all times and in every place, there are also interpretations of organizational-level policies (allowed by Order 200) that may differ somewhat between individual organizations (i.e., OAT sites), where the narcologists have considerable power to "manage" their individual site and can adjust the rules of day-to-day business of OAT provision in accordance with the needs of their daily operations, if they choose to.

One example of this organizational-level policy is take-away dosing. Take-away dosing is when a patient receives a 10-day supply of medication to take home with them. Take-away dosing allows more freedom, less restriction, and more flexibility for the patient. This is a privilege that patients must earn in order to be eligible. To qualify for take-away doses a patient must be enrolled in the "everyday" program for at least 6 months and have a urine test history that is negative for

opioids and sometimes also for other illicit drugs. The patient must be comfortable with their current dosing, not experiencing any withdrawal symptoms, have no administrative violations (i.e., being well-behaved and not violent or disrespectful toward staff). The induction begins with a trial period for one weekend, and then progresses to 3 days, then to a week, and finally a 10-day period. The site narcologist can revoke this privilege at any time as a result of a urine test positive for other drugs including cannabis and alcohol. Narcologists may also test the patient and ask them to come to the site when not scheduled and to bring their remaining medication, at which time they will perform a random pill check to test appropriate at-home dosing to confirm compliance and that no diversion of medication has taken place.

During the pre-crisis period OAT programs were regulated by policies and laws, providers had some discretion regarding the structure of their program and changes at their sites. Some narcologists used this discretion to benefit the patient by creating interpretative flexibility around rules of entry and retention such as not having to prove two previously failed attempts before entry, relaxing harsh rules for administrative discharge, and by allowing take-home dosing privileges (once qualified) so they did not have to come to the site every day. In contrast, some site narcologists used their discretion to strictly enforce the program rules. Providers' decision-making authority determined who/how many clients the site had, and under what conditions these clients were kept. Thus, one example below suggested how providers preferred everyday attendance by clients, whereas the second example illustrates how a provider shaped a program that is more supportive of a certain kind of vulnerable client (i.e., pregnant women).

[Provider 11: I: *"Do you have a possibility to provide medication by prescription here? R: No, we do not. They only have this possibility at Demeyevka. I: Ok, and do you have possibility to provide patients with medication for a number of days or do they have to come every day? R: No. They have to come every day!"*]

[Provider 11: *"If a woman is pregnant, we accept her into the program without any lines, waiting periods and even without medical examination and tests. Such women are offered treatment from the very start."*]

At times, site addiction doctors preferred to control all program's activities and have frequent interactions with the patients to control them.

[Provider 4: *"We have been gradually expanding, very slowly. We can see our opportunities in expanding* only *provided that we issue the medications … Methadone among them… to the patients personally."*]

The authority of individual clinicians was a process rather than a constant, and their criteria of what they thought a good working program was, may transform and change over time as expressed in the following excerpt.

[Provider 17: *"what they love the most is Demidrol. They can shoot up to 40 cc a day. I tried to prevent that particular predilection by providing various explanations and reasons on why that should not be done, but once there were only few patients left in my office with*

*me and one of them said: "You know what? I simply cannot live without this stuff. And this is how I feel all the time no matter what dosage of methadone I receive." Plus, at some point I had a very informative conversation with [Name of foreign expert] on this topic and little by little I changed my point of view concerning this matter. It is not that bad after all, I thought to myself. And there is no reason to kick a patient out of the program like we used to do it before whenever we learned about patients doing something of that kind."*]

Over the years there have been policy changes, promoted by efforts from the providers themselves. Implementation of the Order # 863 was a milestone victory for Ukrainian OAT providers who could now offer different forms of prescription services for those who qualified.

[Provider 17: *"Everything is regulated by Orders of MOH; our main Order is the Order #200 with its multitude of appendixes. Then… we got this new Order #863, which regulates prescription forms… And it was then that we were able to get both – free and charge prescriptions going."*]

The introduction of liquid methadone – a policy decision – was expected to reduce diversion, potentially resulting in fewer discharge occurrences. It would also reduce clinicians' burden from policing the patients to confirm they have swallowed the medication (and not hidden or "cheeked"). Liquid methadone is easier to inventory (because of software) and it tastes better (24).

[Provider 17: *"Because, I am personally not sure at all that all our patients take their medication orally the way they are supposed to; some of them actually inject it; They begin to inject more and more and may easily achieve the dosage when overdose is likely to happen. The only solution of this problem is introduction of the liquid form of methadone. It is a must. That is what they did in the U.S., and they did it for these very reasons."*]

Reducing the opportunity for diversion could positively impact MMT adherence thus creating more "good patients" providers want to see at their site. Good patients will help with the longevity of the program to create a successful image so it will continue to be funded.

[Provider 17: *Some of our patients continue to inject themselves with more methadone to achieve a desired condition. Methadone has become a drug that is much easier to get hold of these days. They have learned to synthesize methadone here just as fine as everywhere else. … I think that things would have become a lot easier if we had a liquid form of methadone as they do in America."*]

Professional recognition for achieving successful patient outcomes was important to clinicians feeling effective in their fields.

[Provider 16: *"Well, who comes to our clinic, the doctors do not go anywhere because (name of head clinician) has created the conditions for work, you should understand, it is very important when you go to work and know that you will be heard, you will be understood, you will get help finally. That's why the staff of doctors are very stable."*]

As expressed by provider 16, the need to be heard is substantial. It seems that clinicians feel they are only heard, and their views are taken seriously by their peers. This echoes extant literature's findings from developed countries, except that their providers were heard about their satisfaction or dissatisfaction across a wider range of domains, and in our study, it seems that providers were at best hearing one another (but overlooked by policymakers).

While in some ways our findings echo results from developed countries (in the general point that economic sustainability is important), our participants were very vulnerable vis-a-vis the authorities that provided funding. They were reticent in expressing dissatisfaction with the existing policies lest it compromised resources for their facility like medication supply and salaries funding. It seems there was more anxiety present than there was dissatisfaction. Our participants expressed feeling more acted-upon than heard.

Since when the participants shared their perspectives, some changes occurred, most notably, the Covid-19 pandemic and the Russian invasion of Ukraine. While at the time of data collection, OAT providers only began to offer several days' prescription of OAT, during Covid-19 lockdown most OAT sites started giving 10-days-worth take-home medication or prescription form of OAT, to all patients to whom it was clinically safe to do so. Thus, the need to treat vulnerable PWIDs during Covid-19 lockdown helped creatively address challenges that have been long undermining programs' success at policy or organizational level, such as streamlining rules of entry and retention, and expanding take-home dosing privileges, items that had been on OAT providers' wish-lists for a while.

## Discussion

In September 2023 as we were finalizing this article, we conducted consultations with five addiction treatment providers in different regions of Ukraine (Kyiv, Donetsk, Zaporizhzhia, Kherson, and Zhytomyr) that have been close to the frontline. We did that to review our findings from data collected in the pre-crisis era and consider lessons that can help better understand the present-day challenges and develop more robust solutions. Questions we discussed with clinicians spoke to the three themes in our findings, including access to resources in humanitarian setting, changes of patient population of their programs, and what factors supported them to continue doing their job despite the non-ending risks, including of physical destruction.

These consultations reinforced that chronic and systemic problems of the healthcare system in Ukraine predate the crisis. Resources that healthcare workers, facilities, and the healthcare system command pre-crisis may be the key factor in predicting how successfully the crisis may be withstood. Noting the abrupt changes that occurred places emphasis on the importance of the providers unmet wish-list items. These perceived pre-crisis deficits are important because the healthcare system was not given warning or time to compensate for them, given the suddenness of the pandemic followed by the war. The crisis placed further demands on providers against fewer resources while chronic system's problems remained.

## Resilience

For decades, while adhering to the Ministry of Health rigid rules narcologists have practiced creativity to withstand challenges like economic uncertainty, shortages of funding and of medication supply,

and understaffing. Yet, participants valued their work, the sentiment rooted in their professional identity where being a narcologist is a calling. This pride in what they do despite the difficulties, is an ethic that helps participants to adapt to challenges, demonstrating resilience.

Our findings revealed the pre-crisis "Normal" or business as usual, i.e., the experiences of Ukrainian addiction treatment providers to work with limited and insecure resources, be creative to overcome hurdles, and seek contentment through work recognized by peers and patients as worthwhile. The resilience of an individual clinician or the healthcare system depends on how much pressure or stress it can withstand without collapsing, and for how long. Covid-19 and other crises have raised the question about the limits and costs of resilience, e.g., in terms of negative physical and mental health consequences for the healthcare workers themselves. According to gyeman-Manu et al. (25) and Ghebreyesus (26) chronic underinvestment in the healthcare workforce coupled with an imbalance between available staff and patients' demand has created persistent labour shortages, exacerbated by Covid-19 pandemic and its aftermath when health workers had to operate beyond human capacity for extended time. One can argue that in Ukraine, operating at or even beyond human capacity pre-dates the crisis.

This brings two important questions. The first is whether experiences of operating with few resources for extended time prior to crisis may increase tenacity of individual providers and of the overall addiction treatment system during the subsequent crisis or conversely make them more vulnerable. The second is the long-term costs of resilience for individual clinicians (e.g., in terms of stress-related chronic health conditions later in life) and for the healthcare system. Answering these questions would require longitudinal research in Ukraine and is relevant across other global regions including the US, and as such, must be approached systematically. To improve population health, advance socioeconomic progress and promote human rights the WHO (27) suggested previously that healthcare workers be considered a human capital investment as independent investments in health will not effectively resolve workforce shortages. Perspectives of Ukrainian addiction treatment providers prior to crisis echo albeit scant research findings from other regions, suggesting they may be potentially affected by crises in ways similar or exceeding Ukraine. The humanitarian crisis that Ukraine is enduring emphasizes the need for better preparedness of the healthcare system to disasters, including paying more attention to healthcare workers' perspectives to reduce resources insecurity in healthcare. This insecurity may have a gendered component, as men including clinicians are drafted during an armed conflict, leaving female health and care workers to carry out the clinical operations. This may present additional challenges as women are underrepresented in decision making and face a 24% gender pay gap according to WHO (28).

According to our findings from OAT providers, challenges that existed before the poli-crisis included economic uncertainty, lack of resources, insufficient structural capacity, understaffing, rigid rules on take-home doses due to risk of diversion and accessing distant site locations which created risk of retention, patient loss, and continuity of care. The precariousness of the economic foundation of the OAT programs was a common concern among clinicians. The long-term sustainability and security of methadone supply was a big concern, alongside economic stability of the program including sufficient funds for staff salaries in the context of uncertainty about the sources and availability of public funds, supply of medication and policies for procuring it.

## Theme 1: economic uncertainty at the institutional level (leading to under-staffing)

Like substitution treatment research in economically developed countries (29), studying Ukrainian clinicians' perspectives before the crisis suggested that ensuring quality of care when scaling up OAT is contingent on sufficiency of resources including medication supply and staffing. Meeting operational needs with adequate staffing has a direct impact on the functional framework of the program as well as on improved patient adherence. Yet, the Ministry of Health policies in the period before the crisis focused on expanding the patient population without creating more healthcare jobs, reducing the number of small clinics, and optimizing, i.e., increasing providers' patient loads, while simultaneously cutting some junior positions like nurses to reduce costs. In the addiction treatment providers' experience, such policies risked undermining the accessibility of OAT sites for patients. While smaller sites, especially in rural areas, may not have been viable economically to stay open, amalgamating sites into larger facilities could result in both clinicians and patients traveling long-distance daily. Previous studies found higher drop-out rates associated with greater distance between patient homes and treatment sites (30, 31). During the crisis greater familiarity of clinicians with patients' circumstances and a trusting relationship, that could be possible if caseloads allowed time for a more holistic approach, proved invaluable for the successful provision of medication, including wider use of take-home doses on a case-by-case basis. This flexibility may be encouraged by structural interventions (32) that facilitate more patient-centeredness without increasing providers' caseloads.

Economic uncertainty that was a fundamental characteristic of OAT providers' experiences pre-crisis, intensified since the Russian invasion. OAT providers were uncertain if the medication supply would be replenished or depleted (33, 34), but our findings indicate that they had to ration their inventory of medication already before the crisis during the "Old Normal". Likewise, the war made staff shortages more acute, but they predated the crisis, especially among the junior frontline staff like nurses, who, unlike more senior specialists, could not perform their work via telehealth but needed to be physically present on premises and thus at high risk if the facility was hit and destroyed.

Remarkably, all the clinicians who shared their war-time testimonies with us as we were interpreting the findings in the current context, had worked in the profession for over 15 years, thus having in-depth knowledge of the pre-crisis context. While providers demonstrated considerable ingenuity and congeniality during the war proving Plato's quote that "necessity is the mother of invention," their insights underscore the need for disaster management planning and preparedness at the healthcare system level. While Ukrainian addiction treatment providers' dedication to care for patients in the most volatile setting is commendable, the lesson from their experience is that improvising may not be the sufficient response, and careful planning of policies and allocation of sufficient resources pre-crisis is needed at the Ministry of Health level.

## Theme 2: structural capacity of the program

Our interpretation of the addiction treatment's providers hesitation to expand their programs to admit more patients citing capacity restrictions (that echoes findings from developed countries) is that the "invisible hand of the market" prior to Covid-19 and the war, tightly squeezed LMIC clinicians by the throat. The OAT providers' experiences during the pre-crisis period suggested that flexibility and creativity to better meet patients' needs was healthcare workers' core value. Yet, their efforts were undermined by insecurity of funding as OAT providers experienced pressures to expand their patient population without additional resources or new staff positions.

As control and surveillance over addiction treatment patients require significant resources from OAT programs' staff (35), this model, common and feasible pre-crisis, had to transform during the Covid-19 pandemic and particularly since the Russian invasion. Thus, transferring stable patients to a 10-day (and occasionally to a 30-day) take-home methadone regimen during Covid-19 crisis, and using this practice after the Russian invasion, not only minimized patients' exposure to risk but also allowed continuity of care despite imminent staff shortages due to illness and war challenges including internal displacement. Thus, trusting relationships between providers and patients nurtured pre-crisis facilitated maintenance of the programs' capacity during the crisis when resources to support the program structures were in short supply. Knowing one another proved to be vital for major solutions during the crisis, as these networks of trust were fundamental for making take-home doses successful during the crisis, and later for getting medications to people who evacuated (33).

After the war crisis hit and one-third of the Ukrainian population was displaced, challenges quickly emerged, and OAT providers had to come up with creative approaches to alternate treatment practices in order to address disruption in medication service delivery. Patients who were already authorized for take-home doses were increased from 10 days to 30 days however patients who were required to present at treatment centers for their medication on a daily basis were at immediate risk for discontinuation. Furthermore, potential out-of-treatment patients whose illicit drug supplies were also interrupted and now seeking OAT were at risk for rapid withdrawal or suicide.

The Network for Improvement of Addiction Treatment (NIATx) model for behavioral health (36), originally introduced in 2014 to aid in the scale-up of OAT, is a bundle of implementation tools that promote the application of exercises to address key problems through coaching strategies and motivational lectures to manage growth change projects for guidance toward improved health policy changes.

According to Altice et al. (33), U.S. NIATx experts held weekly coaching calls with Ukrainian narcologists and the Public Health Centre which helped to guide OAT providers to quickly transition to appropriate treatment practices as the war intensified. NIATx coaches worked with the Public Health Centre to provide guidance to specifically address proper dosing and re-enrollment (37). Altice states that 858 (5%) of the 17,232 patients were lost in the first month along with the closure of 16 (6%) of the 277 OAT sites. Altice reports that 1 month later the OAT program increased by 6.9% due to re-enrollment of 1,136 patients and 6 months later reported an 18.1% increase which included new patients as well as internally displaced patients (33).

As OAT providers, the Public Health Centre, and NIATx coaches collaborated to strengthen the OAT delivery in Ukraine, it became clear that the providers professional pride coupled with the support of these experts became the cornerstone of the success of the OAT program in Ukraine. NIATx continues to guide and empower OAT providers to address emerging problems using evidence-based practices and to create novel strategies for preparedness practices to move forward to further respond to challenges that create barriers to OAT treatment during times of crisis or disruption. It is hopeful that this Shared Decision-Making approach will become the foundation when policymakers reconvene to restructure the program post-war.

Since the war, the need to operate with insufficient resources increased yet became in some sense more palatable to clinicians who felt they were thus expressing solidarity with their countrymen and contributing to a larger public good. As reflected in recent literature (1), Ministry of Health relaxed its rigid rules on take-home doses, allowing Ukrainian addiction treatment providers greater flexibility in providing care to patients, allowing expanded take home dosing (from a 10- to a 30-day supply) in order to continue care and minimize loss of patients. Risk of diversion remained. Clinicians also addressed the need for their patients to access distant site locations during the war, following abrupt interruption of medication and service delivery after reduced access to local pharmacies and closure of 16 OAT program sites in first month. They managed it by relocating to the Western region and communicated via Telegram-SMS to patients and their network of OAT providers (1). Yet, it signified the increased risk of patient loss/retention and continuity of care.

## Theme 3: professional pride

The pre-crisis functioning of OAT programs in Ukraine was a system where the understaffed clinics followed the rules of a top-down structure (5) where the providers had little authority, minimal salaries but ample professional pride to continue the mission. Findings point to systemic barriers pre-crisis however participants were proud of strategies they had developed to overcome the various deficiencies and shortcomings. Despite being over worked, understaffed, and underpaid the sense of identity fueled their continuous strive to do more with less. Yet, although professional pride is a noble, altruistic characteristic, its downside may be the burnout when healthcare workers are forced to operate beyond human capacity for extended times.

Recent research demonstrates (7, 8, 38, 39) that clinicians are expected to indefinitely provide an essential service under any circumstances despite personal risks. At 20 months since the Russian invasion of Ukraine, it appears that the most significant resource on which healthcare workers rely the most is their professional identity or pride, in the most positive sense. When the physical infrastructure crumbled (i.e., missile strikes destroyed clinic buildings) and the administrative rules that govern at the organizational level also crumbled as many processes became logistically impossible, professional pride – the intrinsic motivation to continue doing their work despite all odds out of genuine commitment to their patients – remained intact. Knowing how diligently addiction care providers had always worked with limited resources pre-crisis, being guided by their professional duty, helps better understand how during the crisis providers continue to endure ever increasing hardship without giving

up. Yet, working beyond human capacity may come at great personal cost, and anecdotal evidence during the crisis shared in recent consultations by our informants from the addiction care in Ukraine suggests that overtime, medical staff may experience negative health outcomes despite their heroic tenacity, with some clinicians physically collapsing at workplace, yet others suffering from burnout. Alongside our own studies during the pandemic and during the subsequent war to unpack responses in addiction care (5), research suggests possible ways to assist and support providers during the crisis (1, 15, 40, 41) and maintain their professional well-being by adopting educational interventions through communication platforms like the Network for Improvement of Addiction Treatment (NIATx) model for behavioral health (36). According to Ivasiy et al. (1), participating in collaborative learning interventions with NIATx coaches, helps to alleviate healthcare workers' isolation during the crisis (1, 37).

But as the humanitarian crisis in Ukraine continues, longitudinal research needs to focus on addiction care staff and examine burnout, resilience, and negative and positive coping strategies among frontline clinicians. While this has never been done before in Ukraine or elsewhere, our group has developed a proposal and been fortunate to receive funding to conduct a pilot study among 100 addiction care clinicians in Ukraine. Among other things, we will explore protective and risk factors associated with professional pride over time, e.g., correlations with healthcare workers' burnout and resilience, but also their mental and physical health outcomes. Furthermore, given the emphasis that pre-crisis clinicians placed on support and recognition from peers within the professional community, in the forthcoming pilot study we will include questions on staff participation in professional development activities during the war (online and/or in-person) e.g., seminars, workshops, known to reduce burnout. We will also explore staff and clinical leaders' perspectives on how to bolster both organizational and individual resilience and alleviate burnout, and what they do during the humanitarian crisis to that effect, and whether it is working well and may become candidates for scaling up, or not working in the humanitarian context setting and may need to be de-implemented. We will pay particular attention to whether and how during the crisis mitigating contingencies and working in constant overload mode may become normalized for healthcare providers, i.e., taken for granted. The study will also offer insights into the feasibility of co-producing approaches to alleviate staff burnout with frontline providers (and not only senior clinical staff), giving a voice and engaging them in identifying best practices in their facilities.

In sum, our consultations with addiction treatment providers during the war helped better understand the implications of findings from the pre-crisis study in the current humanitarian context. Reviewing healthcare workers' experiences of coping with the various challenges and the strategies they already used pre-crisis reveals the roots of challenges that pre-date humanitarian circumstances and responses that may also be associated with increased risk overtime. While mental health issues and burnout are escalating among staff during the war, the ongoing healthcare reform to optimize accessibility, quality, and efficiency of healthcare services (42) places further uncertainties on funding for addiction care and current staff's continuous employment given the impetus to shift some addiction care from specialized to primary care facilities with no clear pathways for staff re-employment. Considering the impact of Covid-19 and humanitarian crises, Dr. Hans Henri P. Kluge, WHO Regional Director for Europe (43) stated that healthcare systems will collapse

without proper support if healthcare workers continue facing demands beyond human capacity (25, 26). Since the Russian invasion, experts feared that the Ukrainian health system may fail, destroying the hard-earned successes in high-priority areas of addiction care (33, 44). This also endangers the national and global efforts to combat the spread of HIV, as recent reports from Ukraine indicate an increase of nearly 6% in HIV diagnoses between January 2022 and June 2023, while individuals enrolled on antiretroviral therapy fell by almost 8% (45). While clinicians in addiction treatment in Ukraine maintain the continuity of OAT programs thanks to their deeply rooted professional identity and unique organizational culture despite the destruction and plummeting resources, assistance and respite is urgently needed – and it is not yet too late to provide it. This question also matters to the US, given healthcare staff shortages and a high rate of burnout (46, 47) during Covid-19 particularly among nurses (48–51), yet the government provided little response (52, 53), leaning into traditional expectations of healthcare staff sacrifice (54). The key learning from our pre-crisis research suggests that in low and middle-income countries like Ukraine, humanitarian crises strain already limited resources, leaving essential healthcare workers overlooked (5, 55). By shining a light on these essential addiction care providers' perpetual and pre-crisis concerns, we hope to bring the trend of overlooking healthcare workers' well-being to an end.

## Solutions/call for action plan post-crisis

Economic uncertainties and structural challenges are the chronic diseases of the Ukrainian health care system; they predate the crisis and will likely extend post-crisis therefore we are proposing a long-term wish-list to help bring about a new normality after the humanitarian conditions improve. Despite any challenges, some things remain relevant, including the increased need for OAT, healthcare workers' professional pride and commitment to providing addiction services, and the hopefulness of collaborative approaches using coaching, learning, and support through Shared Decision Making. Thus, we identified some potential strategies toward a solution:

1) Economic uncertainties:
   a. Indexing salaries would not only (partially) provide cost-of-living adjustments during the crisis but would help frontline clinicians feel valued.
   b. The creation of a job bank for re-employment assistance could help displaced healthcare workers who lost jobs due to facility destruction.

2) Structural capacity
   a. Reducing staff during ongoing humanitarian crisis (e.g., due to services restructuring) is unadvisable as it may be associated with increased anxiety and burnout of healthcare providers.

3) Professional identity:
   a. Offering professional development opportunities may be a way to provide respite and offer motivational social support through communication platforms in an effort to sharpen skills, increase confidence and reduce burnout (15, 37, 40, 41).

Ukrainian OAT providers as shown by findings from our pre-crisis study, belong to a professional community that places high value on the success of their treatment programs. The OAT providers commitment to maintain these programs is an example of what Durkheim called organic solidarity, where cohesion develops from mutual support, overall conformity, and a strong sense of professional identity. As the findings suggest, while OAT programs in Ukraine were regulated and need to function to code, there was growing room for flexibility to improve quality of care. This resembles studies from other global regions (56–58) that highlighted the value of a professional community of OAT providers to advance topics like treatment goals and combination therapies. But in trying times, the supportive and protective role of a professional community can attain new levels (especially in the deficit of most other resources and supports).

Professional pride as a reaction to economic uncertainty and structural challenges places emphasis on commitment as OAT providers bring dignity and grace and they respect each other as a community assured by knowing what they do matters. During the Covid-19 pandemic this community was very difficult to maintain due to lockdown and then during the war it became even more complicated as it was difficult to communicate in-person and dangerous to move about the country. Although the ties holding the professional community together are fragile and resource vulnerable (no electricity meant no Zoom) OAT providers find ways to engage with professional development programs if they are only offered (1, 33, 34, 37, 59–61). This tenacity is inspiring and suggests that it can still be saved and rebuilt. Experience is the best teacher; let us learn from this experience. The Ukrainian proverb *"a hungry wolf is stronger than a satisfied dog"* means that it is better to be hungry for progress than to be satisfied with being stagnant.

4) Government can support healthcare providers by inviting dialogue and listening to the providers wish-list requests for serious consideration during the rebuild. Paying serious attention to healthcare providers' well-being is imperative as burnout of healthcare providers during crisis is a growing concern that can have a global impact (6, 7, 9, 16). Importantly, the co-production approach common while developing successful interventions for service users must be also taken on board concerning interventions and policies directed at healthcare workers. Trust them to be their own saviors because they know what works and what does not through their lived experience. In post-humanitarian context, including addiction treatment providers' vast experience into the development of treatment systems given the dearth of resources may prevent a cascade of negative implications within the primary care health care system, the Criminal Justice system, school systems and society in general.

5) Foster Shared Decision Making: This concept was mostly used in a narrow sense as it has historically meant to bring patients into the conversation when talking about the solution of their own problems (62–65). We suggest exploring the implementation of this technique in relation to providers and their dealings with policy makers who decide the future of SUD care in Ukraine (55). OAT providers have previously had little influence and their voices were dismissed. The Ukrainian OAT providers are (re-)writing the rulebook and other

countries are paying attention wondering how they are managing this crisis a year (plus) into the war. Here, SDM between providers and policy makers could help to carve in roads as a way forward postwar. Thus, as part of our pilot study of addiction treatment clinicians in Ukraine, we will conduct a workshop with governmental officials from the Ukrainian Ministry of Health and frontline addiction treatment staff to discuss local adaptations to support the staff and continue providing addiction treatment during and after the humanitarian crisis. We will discuss the costs/sacrifices of sustaining addiction care provision in terms of clinicians' own health, their organization's staffing and patient care provision, economic remuneration, and other areas, from the perspectives of frontline staff. We will ask about any strategies and programs set up in their clinic since the Russian invasion to support staff (paying particular attention to professional development opportunities which we know from the literature may alleviate stress and prevent burnout including in humanitarian settings). The focus on lived experiences of frontline staff is of paramount importance to enabling bottom-up approaches to future interventions, and shape recommendations for individual staff, clinical directors, as well as for the government / policy making. As Shared Decision Making (SDM) and co-production is widely employed in work with patient populations, we will synthesize, in collaboration with the frontline addiction treatment clinicians, the insights from the workshop to form the basis for a report of recommendations that may ultimately improve patient outcomes, protecting addiction care in Ukraine from collapse. For example, inviting clinicians' input on how to optimize roles of existing staff to scale-up OAT provision by expanding the take-home OAT on a case-by-case basis may alleviate clinicians' perceptions of being overworked and underpaid (66). In the emergence of the new normal, communication between OAT clinicians and policy makers would be key to improve quality of care, improve providers' job satisfaction and retention, and improve patient outcomes, by institutionalizing best practices within the clinicians' professional community. Co-production by addiction providers could be the needle that weaves the common threads of wisdom to create a tighter textile of policies.

Our participants in the pre-crisis study, as well as addiction treatment providers with whom we consulted during the war to better understand the study's current implications, entrusted us with their stories in the hopes we would understand. Not being spoiled by attention from either researchers or policy makers, addiction care providers in pre-crisis Ukraine had shared with us what they saw as the system's shortcomings, and we ought to shed light on it after all these years. It is time that healthcare workers' input is recognized, and their well-being is supported, and it is always better late than never.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## Ethics statement

## Author contributions

## Funding

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## Conflict of interest

## Publisher's note

## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1259488/full#supplementary-material

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# Pills and the damage done: the opioid epidemic as man-made crisis

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The prescription opioid epidemic has slowly evolved over the past quarter century with increasingly detrimental consequences for public health. Man-made crises are often unforeseen and characterized by a situation without natural causes where — because of human intent, error, negligence, or the failure of manmade systems — the level of needs in the population exceeds available resources to counter the problem. This paper presents the prescription opioid epidemic as a man-made crisis and explores the public health impact of opioid manufacturers and other industries producing commodities with addictive potential as a shared vulnerability among countries. We examine this concept within the framework of the commercial determinants of health. We address three key aspects of the commercial determinants of health: (1) Cross-industry mechanisms, (2) policy inertia, and (3) the role of industry in science. Within cross-industry mechanisms, we explore parallels between prescription opioid epidemic and unhealthy commodity industries in terms of marketing, corporate use of misinformation, and diversionary tactics. Next, we examine how policy inertia has dominated the slow response to this man-made crisis. Lastly, we discuss how results from clinical trials are used as a key marketing strategy for drugs. The origins of the prescription opioid epidemic may be traced to innovations in drug development with the promise of improved pain management. However, through multiple factors, including fraudulent marketing from pharmaceutical industry and policy inertia, the resulting crisis represents a multi-system failure of regulation exploited by corporate greed.

KEYWORDS

analgesics, overdose, misuse, prescription opioids, poisoning, oxycodone, addiction

## 1 Introduction

In this "Perspective" piece, we present the prescription opioid epidemic as man-made crisis within the framework of the commercial determinants of health (CDOH). By definition, man-made crises lack natural causes and result from human intent, error, negligence, or the failure of manmade systems (1). Prescribers are recognized to have played a central role in generating the oversupply of opioids (2). However, we cannot look at prescriber behavior in isolation, without considering how pharmaceutical industry benefitted from weak regulations and influenced prescriber education to advance its agenda of opioid sales, at the expense of the lives of thousands (3). The impact of corporate action on health outcomes is indeed focus of the CDOH, a concept first proposed by West and Marteau in 2013 (4) as 'factors that influence health which stem from the profit motive'. At the example of the tobacco industry and cigarette

sales, West and Marteau describe the corporate profit motive as detrimentally opposed to public health.

A wide range of definitions of the CDOH now exists, which a recent consensus paper in The Lancet (5) integrates as: "the systems, practices, and pathways through which commercial actors drive health and equity." This neutral definition acknowledges that prescription opioids can have both positive and negative effects on human health. Indeed, Babor and Ferreira-Borges describe the opioid epidemic as a "prime example of the growing importance of CDOH" (3).

In the United States (US), the epicenter of the epidemic, prescription opioid overdose deaths have quadrupled since 1999 and been directly linked to the country's declining life expectancy (6). The resulting level of treatment needs for opioid use disorder exceeds available resources to counter the problem (7). Looking beyond North America, misuse of opioid analgesics is now spreading globally and increasingly affecting parts of the Middle East, Africa, and Northern Europe, including Scandinavia (8, 9). As a team of authors, we are based in Norway, where prescription opioids have overtaken heroin as the most frequent cause of overdose deaths since 2016 (10, 11). Despite these trends, the onset of an opioid epidemic of North American proportions currently appears unlikely (12, 13). The reason might be found in differences in the European system (e.g., access to free or low-cost healthcare, fewer automatic prescription refills, lack of direct-to-consumer advertising for prescription medications) (14, 15).

Our aim here is not to appraise such differences, but to use the CDOH framework to describe the potential influence of the opioid industry (and other industries producing commodities with addictive potential) on public health as a shared vulnerability among countries. The core subject is to improve the understanding of how the corporate profit motive has driven opioid overprescribing and mortality. Thus, we apply three key aspects of the CDOH to the opioid epidemic: (1) Cross-industry mechanisms in the marketing of potentially addictive products, (2) policy inertia and lack of government intervention as evidence of health harm emerges, and (3) the role of industry in science.

## 1.1 Cross-industry mechanisms: what parallels does the prescription opioid epidemic have with other industries that create significant health damage?

### 1.1.1 Parallels in marketing with unhealthy commodity industries

Alcohol, tobacco, and ultra-processed foods (UPF) are typically considered unhealthy commodities, i.e., products that *per se* cause significant health damage, "aimed at, and accessible to, large numbers of consumers," and "highly profitable because of their low production cost, long shelf-life, and high retail value" (16, 17).

Due to their intended medical use, prescription opioids do not constitute unhealthy commodities. Their prescription-only status also makes pharmaceutical opioids less accessible than alcohol and tobacco (legal access restrictions by age and/or retail venue) and UPF (no restrictions), thus attracting a much smaller customer base. Nonetheless, several cross-industry similarities in marketing can be identified.

Firstly, alcohol, tobacco, and prescription opioids are all commodities with potential for addiction-driven consumption (18). Consumers

addicted to these commodities tend to consume at least daily and in greater amounts than non-addicted consumers, meaning that their excess consumption drives consumer spending and accounts for most corporate profits ("addiction surplus") (18). As Adams and Livingstone illustrate (19), corporations are invested in establishing daily use early in customers' lives and maintaining individual excess consumption. To this end, corporations use misinformation to lobby against changes in legislation or clinical guidelines that seek to limit product access (19).

Secondly, due to their low production cost, low mass (135 mg), and no storage requirements (20, 21), OxyContin (and other prescription opioids) are ideal for international export. Indeed, in the 2010s, as US sales of OxyContin by the Sackler family-owned Purdue Pharma were stagnating because of prescribing restrictions and possible saturation of the domestic market (22), opioid industry began to target low- and middle income countries (LMIC). A 2016 LA Times investigation (23) reported that Mundipharma, i.e., a conglomerate of companies also belonging to the Sacklers, has undertaken lobbyism activities "right out of the playbook of Big Tobacco" to expand OxyContin into markets in Africa, Asia, Latin America, and the Middle East. In addition to hosting seminars targeting prescribers, this has involved aggressive marketing such as patient discounts for prescription opioids (foot-in-the-door technique) as well as policy interference in the context of poor legislation and regulation in LMICs, driving opioid consumption in places ill-prepared to deal with its negative impacts on public health (23). The provision of product discounts can have devastating unintended consequences in LMIC. In the 1970s, thousands of infants died from malnutrition after Nestlé had distributed free product samples of infant formula to parents in African and Asian hospitals (24). Mothers ceased breastfeeding (considering it inferior to formula), mixed formula with unclean water, or diluted it too much after the free samples had run out (24).

### 1.1.2 Corporate use of misinformation

In 1996, the American Pain Society advocated that healthcare providers should screen for pain as "fifth vital sign" (P5VS initiative), which was subsequently adopted by the US Veterans Health Administration in a national strategy to include mandatory pain screening and pain-related patient satisfaction questions (25). Coinciding with the P5V5 initiative, Purdue Pharma brought to market OxyContin, which it was advertising as a novel opioid pain medication that was long-acting and therefore "less prone to abuse" (26, 27).

As early as 2003, the US Drug Enforcement Administration established that Purdue Pharma's "aggressive, excessive and inappropriate" product marketing under-communicated risks and "very much exacerbated" abuse of OxyContin (23). OxyContin marketing sought to normalize prescription opioid use by shaping public opinion through direct consumer-advertising with the promise of pain-free living (such as the slogan "There Can Be Life with Relief") (28). In parallel, thousands of prescribers were targeted with misinformation, including a 2007 American Medical Association training on pain management "made possible by an educational grant from Purdue Pharma" (29, 30).

At all-expenses-paid seminars involving supposedly independent "key opinion leaders" such as pain management specialists and patient charities, doctors were encouraged to "overcome their opiophobia" and prescribe opioids for a wider range of medical indications (31). As Pettigrew et al. (30) write: "Purdue Pharma set up "pain groups" as

part of a wider "pain movement" to promote the use of the opioid OxyContin to treat a wide range of conditions – from cancer and severe pain management initially to more minor conditions, and increasingly higher doses – while denying it was addictive." In Australia for example, Mundipharma sponsored over 3,000 pain-related educational events from 2011 to 2015 which targeted doctors and nurses in the interest of opioid promotion (32). An internal Purdue Pharma analysis found that physicians who attended these events wrote more than double the number of OxyContin prescriptions of non-attendees (23). The role of pharmaceutical industry in provider education is thus problematic (31).

### 1.1.3 Diversionary tactics

By using self-serving slogans such as "drink responsibly" or "smoke responsibly," industry tend to shift responsibility onto the individual to detract from corporate harm. Notably, "responsible" behavior is left purposely vague in these slogans (5).

In its response to the opioid crisis, Purdue and its owners, the Sackler family, strategically blamed consumers for their "irresponsible use" of OxyContin. As Radden Keefe (33) writes in his history of the opioid epidemic: "People did abuse these drugs, Arthur [Sackler] conceded. But the real explanation for this phenomenon was not any intrinsically addictive properties of the drugs themselves. Rather it was a reflection of the addictive personalities of the users themselves. What Purdue should do, he decreed, was "hammer on the abusers in every way possible." They are "the culprits" he declared. "They are reckless criminals.""

On 30 May 2023, a New York court of appeals granted immunity to the Sackler family, ruling in a $6 billion USD settlement agreement (34) that all family members will be protected from current and future lawsuits over their role in Purdue Pharma's opioid business (35). The case has been moved to the US Supreme Court where it is currently on hold and will be reviewed in December 2023 (36).

## 1.2 Policy inertia: what are the reasons for the slow response to man-made crises?

Another commonality between the North American opioid epidemic and other man-made crises is the collective experience that "had we intervened sooner the current situation could have been different or perhaps even averted" (7). What are then the reasons for our historically slow response to silent epidemics that unfold before our eyes? And how does our response to man-made crises differ from our management of "natural epidemics"?

A particular challenge to public health arises from the fact that, at the level of individual trajectories of drug use, adverse health effects can often only be detected many years after first drug exposure. Rhodes and Lancaster (37) make a compelling case that the short-term focus of early warning systems and outbreak detection is unsuitable for the description of the "slow death" or "slow emergency" of opioid overdose. In Europe, the average age of drug-induced deaths is 41 years (38), occurring likely more than two decades after the onset of drug use in many individuals. Statistically speaking, overdose death is a rare event (39) relative to the number of people who use opioids and their frequency of use, which makes time-sensitive changes in the rate of overdoses difficult to detect at population level.

The duration of the time window between initial use of a drug and the occurrence of drug-related harms will likely also depend on the

drug's potency and its abuse potential. For instance, the arrival of illicitly manufactured fentanyl (a highly potent full opioid agonist) on the drug market in US cities around the year 2013 almost immediately led to a rise in overdose fatalities, which is now considered the onset of the "third wave" of the US opioid epidemic (40). Tramadol, by contrast, is considered a 'weak opioid' with mixed mechanism and lower abuse potential than other opioid analgesics (41, 42). According to the World Drug Report (9) an epidemic of non-medical use of tramadol is currently unfolding along trade routes in North Africa, West Africa, the Near and Middle East and South-West Asia, posing great health risks. First indicators of harm have included the increase in treatment demand for tramadol use disorder in some African as well as local reports of high rates of tramadol involvement in traffic accidents (9, 43). However, due to lack of epidemiological data on drug use and routine toxicology testing in the affected regions, the current scale of this epidemic in the making is unknown, and public health interventions remain largely absent.

In man-made crises, availability of epidemiological data is not enough for change to occur. As early as 2003, the US FDA issued a warning letter to Purdue Pharma over its omission and minimization of the safety risks associated with OxyContin in the product's marketing materials (28). Two years later, Cicero et al. (44), reported an increase in nonmedical use of OxyContin "among street and recreational drug users" based on epidemiological surveillance data (RADARS; 2002–04), concluding that "steps need to be taken to reduce prescription drug abuse."

Yet, policy inertia from both North American regulatory agencies (Health Canada, US FDA) and relevant public health bodies prevailed. This enabled Purdue Pharma's ongoing OxyContin sales to cause addiction and death in the population – at the expense of individuals, governments, and non-governmental organizations having to meet these costs.

Using the notion of inductive risk to illustrate the moral severity of errors at the post-marketing approval stage, Bavli and Steele (45) argue that Health Canada could have prevented significant public health harm if it had applied a less strict standard of evidence as requirement for revisions to the OxyContin product monograph, which understated the risk profile of the drug.

Within the addiction care system, many evidence-based practices were available in the first wave of the opioid epidemic, including the expansion of access to medications for opioid use disorder (methadone or buprenorphine treatment; naloxone for overdose reversal) and harm reduction measures (e.g., needle and syringe programs). Still, these were not systematically being implemented until *after* the Unites States entered the second and third wave of the opioid epidemic, with increases in heroin- and fentanyl-related deaths beginning in 2010 and 2013, respectively (46). In the meantime, opioid overdoses and mortality had escalated, leaving North American healthcare systems increasingly unable to cope.

## 1.3 What is the role of industry in science?

For pharmaceutical industry, scientific publication of results from clinical trials is a key marketing strategy for drugs. However, in clinical trials conducted or sponsored by industry, potential bias in the selection of study design and outcomes as well as lack of transparency in reporting threaten patient safety. As Bero (47) writes, "empirical research demonstrates that pharmaceutical […] industry funding

biases human studies towards outcomes that are favorable to the sponsor, even when controlling for other biases in the methods."

Indeed, in their retrospective analysis of regulatory data submitted by Purdue Pharma to Health Canada for the approval of OxyContin, Pappin et al. (48) determined that "[n]one of the trials sponsored by Purdue Pharma sought to meaningfully assess the risks of misuse or addiction associated with OxyContin. The trials were short in duration (maximum length was 24 days) and only assessed safety and efficacy of a 12-h dosing interval. Also, the two trial reports that explicitly mentioned (but did not formally evaluate) the risk of misuse were not published."

Importantly, Purdue Pharma external funding awards were not limited to specific project grants (e.g., for clinical trials) but has also included institutional donations from Sackler family charities to leading universities in the United Kingdom and US (49). A recent New York Times (2023) investigation documented that – In a clear conflict of interests – the National Academies of Sciences, Engineering and Medicine, a nongovernmental institution, received approximately $19 million in Sackler donations while advising the US federal government on opioid policy (50).

These institutional donations are akin to former tobacco industry funding of universities to conduct studies into various health topics – so-called "red herring" research that could serve as distraction from the corporate agenda of boosting tobacco sales (30, p. 53). Within the opioid industry, corporate funding of service user initiatives (51) or the recent Purdue Pharma announcement of investment into 'opioid rescue medicines' (35) arguably fall in the same category. Analogous to pharmaceuticals and tobacco, the negative impact of the "funding effect" on research agendas and integrity has been documented for the alcohol and, more recently, cannabis industries (52).

## 2 Discussion and conclusion

The origins of the prescription opioid epidemic may be traced to innovations in drug development with the promise of improved pain management. However, through multiple factors, including fraudulent marketing from pharmaceutical industry as well as policy inertia, the resulting crisis represents a multi-system failure of regulation exploited by corporate greed.

Unlike natural disasters or viral disease outbreaks that are confined in space or time, manmade crises develop gradually as commercial determinants affect health through proximal and distal pathways. Due to a lag in outcomes, their onset and initial evidence of harm are more challenging to identify, which can hinder early public health response.

The prolonged US opioid crisis has accounted for a death toll far higher than the country's natural disasters. Still, it was only declared a Public Health Emergency in 2017 (53) – more than two decades after OxyContin became commercially available. In the meantime, opioid prescribing and related deaths continued to disproportionately affect US communities with greater levels of deprivation (54). As we have demonstrated through application of the CDOH framework, the prescription opioid epidemic exemplifies what West and Marteau (4) described as "the tension between wealth- and health-creation," where public health is fundamentally at odds with the profit motive of industries producing addictive commodities.

To contend with industry influence in science, including the growing role of industry-academia collaborations, society needs to set up more stringent mechanisms for declaring conflicts of interests at individual and institutional level as well as corporate lobbying activities. This becomes increasingly relevant for the addictions field as corporations are heavily investing in lobbying for exemptions from the international prohibition of cannabis and psychedelics, promoting their therapeutic or recreational use (55, 56). Moreover, real-world data as well as transparency in the public documentation of clinical trial data (57) and regulators' data interpretation are needed (48).

To prevent future crises involving addictive commodities from occurring, regulatory agencies will require appropriate staffing capacity to review safety data and promotional materials (31). At the post-approval stage, regulators should apply a less strict standard of evidence of product-related harm in individuals to avoid population-level adverse consequences (45). If a crisis develops, industry-independent funding for rapid assessments will be crucial to gather evidence and inform health policy.

Finally, at the benefit of corporate profits, medical systems are designed to initiate patients on drugs, not take them off (58). Despite minimal evidence of their long-term effectiveness, overprescribing of opioids has put patients at risk of dependence, side effects, and drug–drug interactions (59). Research funding is urgently needed to study safe strategies for deprescribing opioids and other medications with potential for addiction or physical dependence.

To quote the conceptualization of the CDOH by Gilmore et al. (5), pharmaceutical companies will "need to meet the true costs of the harm they cause, governments will need to exercise their power in holding [these] commercial entities to account, and [clinical] norms [and practices] need to be reshaped in the public interest."

## Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## Author contributions

RM: conceptualization, writing of original draft, review and editing. DE: conceptualization and review. SS: conceptualization and review. TC: conceptualization, review and editing, and supervision.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

RM declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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# Adapting the ADVANCE group program for digitally-supported delivery to reduce intimate partner violence by men in substance use treatment: a feasibility study

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**Introduction:** COVID-19 restrictions created barriers to "business as usual" in healthcare but also opened the door to innovation driven by necessity. This manuscript (1) describes how ADVANCE, an in-person group perpetrator program to reduce intimate partner violence (IPV) against female (ex)partners by men in substance use treatment, was adapted for digitally-supported delivery (ADVANCE-D), and (2) explores the feasibility and acceptability of delivering ADVANCE-D to men receiving substance use treatment.

**Methods:** Firstly, the person-based approach and mHealth development framework were used to iteratively adapt ADVANCE for digitally-supported delivery including conceptualization, formative research, and pre-testing. Then, a non-randomized feasibility study was conducted to assess male participants' eligibility, recruitment, and attendance rates and uptake of support offered to their (ex)partners. Exploratory analyses on reductions in IPV perpetration (assessed using the Abusive Behavior Inventory; ABI) and victimization (using the revised ABI; ABI-R) at the end of the program were performed. Longitudinal qualitative interviews with participants, their (ex)partners, and staff provided an understanding of the program's implementation, acceptability, and outcomes.

**Results:** The adapted ADVANCE-D program includes one goal-setting session, seven online groups, 12 self-directed website sessions, and 12 coaching calls. ADVANCE-D includes enhanced risk management and support for (ex)partners. Forty-five participants who had perpetrated IPV in the past 12 months were recruited, forty of whom were offered ADVANCE-D, attending 11.4 (SD 9.1) sessions on average. Twenty-one (ex)partners were recruited, 13

of whom accepted specialist support. Reductions in some IPV perpetration and victimization outcome measures were reported by the 25 participants and 11 (ex)partners interviewed pre and post-program, respectively. Twenty-two participants, 11 (ex)partners, 12 facilitators, and 7 integrated support service workers were interviewed at least once about their experiences of participation. Overall, the program content was well-received. Some participants and facilitators believed digital sessions offered increased accessibility.

**Conclusion:** The digitally-supported delivery of ADVANCE-D was feasible and acceptable. Remote delivery has applicability post-pandemic, providing greater flexibility and access. Given the small sample size and study design, we do not know if reductions in IPV were due to ADVANCE-D, time, participant factors, or chance. More research is needed before conclusions can be made about the efficacy of ADVANCE-D.

# 1 Introduction

Intimate partner violence (IPV) perpetration involves any behavior causing physical, sexual, or psychological harm, including aggression, sexual coercion, psychological, and financial abuse and coercive control (1). While IPV occurs in all relationships (1–4), women experience greater injury (1, 5, 6) and are six times more likely to be murdered by their intimate partner than men (7). Multiple risk factors contribute and interact at individual, relationship, community, and societal levels to increase the likelihood of IPV perpetration, including substance use, mental health problems, adverse childhood experiences, anger, hostility, poor executive function, low empathy, relationship conflicts, and holding sexist attitudes (8–12). Many risk factors are elevated among men who have substance use problems (13, 14), potentially explaining the higher prevalence of IPV perpetration among this group compared to the general population (8, 14–16) and highlighting that targeted perpetrator programs are needed (14, 17, 18). Limited evidence shows what works to reduce IPV perpetration by men who use substances (19), but programs that include trauma and substance use components show promising results and/or greater reductions in perpetration (20, 21). Regardless, men in substance use treatment are underserved by perpetrator programs (22, 23) and often considered unsuitable for such programs due to their substance use (24). Men who use substances are also most likely to drop out of perpetrator programs (14, 23, 24), suggesting alternative and tailored approaches are required. We developed the ADVANCE perpetrator group program (25–27) to address the complex interplay between substance use and IPV perpetration in the context of intoxication, withdrawal, craving and acquiring substances (28–30), neglected in other programs. Our research highlighted the importance of addressing sexual jealousy and entitlement, the wider dynamics of power and control, and psychological vulnerabilities (29–31).

Pre-pandemic there was little evidence about remotely delivering perpetrator programs online (32). One study highlighted enhanced accessibility and flexibility, but that access to hardware, broadband, and private space posed challenges (32). Early in the pandemic, the limited guidance on remote delivery focused on reducing short-term risk via safety-planning, including for co-habiting survivors and children, and de-escalation (33, 34). As remote delivery of substance use and perpetrator programs continued, the need to carefully and specifically adapt perpetrator programs and integrated survivor support (35) for digital delivery, drawing on evidence and theory became clear, particularly because IPV and substance use reportedly increased during lockdown (36–40). We therefore adapted our in-person ADVANCE group perpetrator program (25) for remote delivery.

# 2 Aims

We present (1) the process of iteratively adapting our in-person group for digitally-supported delivery (ADVANCE-D) for men in United Kingdom substance use treatment settings, (2) qualitative and quantitative findings from a multi-center, non-randomized feasibility and acceptability study, with a nested process evaluation, and (3) preliminary outcomes on IPV perpetration and victimization.

# 3 Methodology

## 3.1 Iterative adaptation of ADVANCE

### 3.1.1 Overview of methodology

The person-based approach (41, 42), and mHealth development framework (43) were used to iteratively adapt ADVANCE for digitally-supported delivery during August 2020–June 2021, involving:

 i Conceptualization: Scoping reviews of literature and emerging guidance on delivering psychosocial interventions remotely and/or digitally were undertaken. Given the timeframe of the

adaptation, only evidence published pre pandemic or published early into the pandemic (in 2020) was included in the literature reviews. Through our existing Learning Alliances, professionals from criminal justice, substance use and IPV perpetrator and survivor organizations were consulted to identify remote delivery and risk management practices.

ii   Formative research: Multiple rounds of consultations with key stakeholders—staff from substance use services, Learning Alliance members, men who used substances, and IPV victims/survivors—were conducted and proposed approaches and materials were grounded in their reality and practice. Following the conceptualization phase, it was decided that a blended approach would be used to deliver ADVANCE based on the available evidence, including online individual and group sessions, website sessions, and coaching calls. The website sessions would use an "online coach" to "deliver" ADVANCE material from the original intervention, and guide men through sessions. It was also decided that an (ex)partner's version of the website, for (ex) partners to view would be created. Nominal group technique (44) was used to reach consensus with stakeholders from the two Learning Alliances on the delivery model options and on the look and feel of the online coach and of the website sessions. Six men with lived experience of using IPV and/or substance use (from here on referred to as men with lived experience) were consulted on the paper prototype of the website sessions, their experiences of using technology and ideas around how to enhance engagement (45). These consultations helped us understand how we could best deliver and communicate digital content. Comments were fed back to the developers and designers at Rochester Institute of Technology to inform the development of a digital prototype of the first three website sessions including the online coach.

iii   Pre-testing: Individual consultations (using videocalls) were held with eight male substance use treatment service users and four female IPV survivors on the male and (ex)partner website prototypes, respectively. They were given a link to a test website, asked by a researcher to share their screen and to "think aloud" while using the website (41). Their views about intervention flow, structure and design were recorded. Decisions on whether to modify were based on whether changes were likely to impact acceptability, feasibility, persuasiveness, motivation, and engagement (41) using MoSCoW (must-have, should-have, could-have, and will not-have) prioritization criteria (46). Pre-testing was completed remotely using a secure online meeting platform due to COVID-19 restrictions.

Below, we combine the findings from these three stages of adaptation to explain key decisions made about: mode of delivery, website design and features, addressing digital poverty (i.e., being unable to interact with the online world due to financial or geographical barriers, or not having the skills to do so), therapeutic alliance and group size, and enhanced risk and safety management. We then give an overall description of the adapted program (ADVANCE-D). The consultation and user testing were conducted in the earlier stages of the COVID-19 restrictions when staff and service users may have been less familiar with using online programs.

## 3.1.2 Key decisions made about the adapted version

### 3.1.2.1 Choosing a blended mode of delivery

Our early consultations with key stakeholders at the outset of the pandemic highlighted that many criminal justice and substance use services decided not to migrate to online delivery, opting for telephone check-in sessions instead, to monitor risk, safety, relationship status, and substance use, and to signpost people to contact other appropriate services, or make necessary referrals. Trials of guided (patient communicates with a health care professional) and unguided internet-based cognitive behavioral therapy (iCBT) pre-COVID-19 found that these approaches were acceptable to patients and effective in reducing depressive symptoms (47) and alcohol use (48). Guided iCBT was found to be more effective than unguided iCBT (47, 48). Blended care combining iCBT and face-to-face sessions with a therapist also shows positive outcomes (49), comparable to face-to-face CBT alone (50). Other studies have shown significant improvements in outcomes for programs that combine self-directed support with telephone facilitation (51, 52). We chose a blended digitally-supported delivery as the best approach to deliver ADVANCE-D remotely, combining online groups, self-complete website sessions to practice what was learned in the groups and phone or videocall coaching/support from a facilitator (52–54). Figure 1 summarizes the ADVANCE-D program theory and Figure 2 presents the adapted model. The offer of personal contact and support to promote use of the material and monitor risk was based on evidence that this approach showed better outcomes than online interventions without such support (47–54). This was also requested by men with lived experience and key stakeholders.

In one study, men attending behavior change programs suggested that a digital intervention could encourage men to consider the impact of their behavior on their families, particularly their children (55). The ADVANCE-D website sessions were designed to repeat and build on the content of the group sessions, giving participants this chance. The men we consulted wanted the website sessions to include recaps, avoid quizzes or tests, take <30 min to complete and provide "recognition" for completing sessions. These were all included in the website sessions. They also requested an introduction session to learn how to use the technology and to have reminders of when to complete the website sessions which were also incorporated into delivery.

### 3.1.2.2 Website design and features

Static educational materials (i.e., unguided self-help content), lead to low engagement (53). Factors that increase engagement include a sense of "connectedness"—that is, interactivity, personalization through tailored content and/or feedback, such as by facilitators exploring ways that participants can incorporate learning into their day-to-day, feeling informed, supported, and understood, and getting reminder emails to complete sessions (56–58). ADVANCE-D website sessions incorporated personalization—the online coach "led" interactive sessions (e.g., participants were asked to input how they were feeling and the online coach acknowledged if they were feeling low). Sessions integrated film clips and multiple-choice question and answers, to increase engagement. "Try it out" activities (i.e., "homework" was set at the end of each website session) encouraged participants to incorporate learning into their daily lives. The sessions were followed up with phone or videocall coaching and tailored support from a facilitator to promote engagement and monitor risk.

**FIGURE 1**
Theory guiding the ADVANCE intervention.
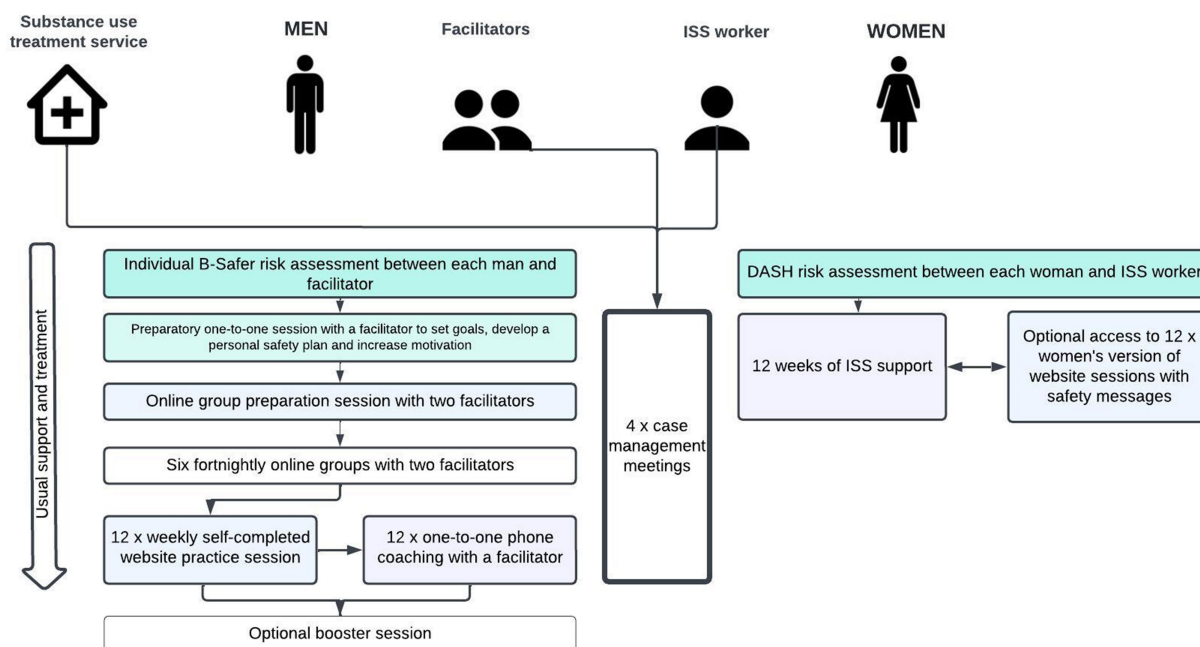


**FIGURE 2**
Overview of ADVANCE-D intervention.

Similar to another patient feedback study of avatar-based interactive technologies for co-occurring substance use and IPV, our user consultation wanted the digital coach to look like a real-life professional rather than a cartoon (59).

Disclosure of sensitive information (including drug use and IPV victimization) was more likely to avatars than face-to-face (60). Men with lived experience requested that all content spoken by the online coach was also provided in text. Evidence also suggests that new visual information should be explained with audio rather than text (61).

Think-aloud videocall interviews to review the digital prototypes with men with lived experience suggested changes to the website for ease-of-use, clarity and visual impact. They requested the inclusion of a progress bar to allow the user to know how much of each session had been completed. Ability to monitor progress also influences engagement (62, 63). These were all implemented as well as

participants having the ability to take a break from the website session and pick up where they left off when they logged in again.

### 3.1.2.3 Addressing digital poverty

Initial consultation with service users and service providers highlighted that access to both hardware and mobile data could hinder engagement with ADVANCE-D. This was supported by research in United Kingdom community drug treatment services that found only 57% of the 83% of clients who owned a mobile phone had a smartphone, and that 72% of clients used pay-as-you-go contracts (64). Therefore, providing tablets and data to participants in this study was required to facilitate engagement. Service users and providers also highlighted a potential lack of digital literacy and suggested providing knowledge about how to use the software and access to technical support. To address digital poverty and enhance digital literacy (64–66), we sent ready to use tablets (preference from

our consultation over smartphones) with front-facing cameras with 4G connectivity and headphones to participants, and research staff provided technology support by phone or email, alongside a "how to guide" to use the technology and platform. Men with lived experience suggested that contingency management should be linked to pro-social activities (e.g., cinema, gym membership etc.), but such activities were not always possible during COVID-19 restrictions. They also highlighted that the cost of mobile data may contribute to lower engagement. Therefore, we later decided to provide free monthly mobile data contingent on attendance, and men who completed ADVANCE-D were permitted to keep the tablet after the study ended as a further incentive. This decision was supported during a later consultation with people with lived experience and service providers.

### 3.1.2.4 Therapeutic alliance and group size

Facilitators of online groups must pay attention to building therapeutic alliance and to group process, as these are linked to positive treatment outcomes (67). Participant cohesion can be developed through group agreements. Paying attention to social cues and signs of emotionality (facial expression, tone of voice, or body language) and asking more questions than usual to clarify responses and reactions can help build therapeutic alliance online (53). These techniques, as well as attending to group dynamics, giving equal time and attention to all members of the group and promoting positive, respectful communication, were built into the ADVANCE-D model, and were emphasized in training and integrity support meetings. Studies of therapeutic groups, comprising 5–13 participants, suggest group size does not predict outcomes (68). Slightly smaller groups are more appropriate for participants with learning disabilities or behavioral problems or for CBT-based groups due to level of skills imparted (69). Therefore, ADVANCE-D sought to recruit between 6 and 12 participants for each group.

### 3.1.2.5 Enhanced risk and safety management

Concerns around delivering perpetrator programs online included lack of face-to-face cues, difficulty in managing complex group dynamics and limitations in modeling of gender equality via co-facilitation (70). Our consultations with key stakeholders and guidance available at the time (33, 34, 70), emphasized the importance of a group agreement, including rules on not misusing technology (e.g., for illegal or abusive purposes), keeping cameras on to allow facilitators to gauge potential intoxication and substance use, personal identifying items (e.g., photos of children) to be out of range, and not attending/completing sessions intoxicated. Participants were asked to complete and join sessions in a private room where they could not be overheard and to use the headphones provided if necessary. Facilitators were asked to pay attention to participants' emotional wellbeing, substance use, home living situation, and to act on any change in risk related factors.

ADVANCE-D was structured to ensure that group members were not left feeling triggered to enact abuse or emotionally dysregulated after online groups or website sessions. Check outs, one-to-one coaching calls and specific ADVANCE-D materials, including use of self-soothing sensory items and relaxation techniques (used in the original ADVANCE program) were identified as strategies to help manage difficult thoughts or emotions. We decided that scheduling times for coaching calls with facilitators after completing website

sessions would encourage participants to refrain from substance use before/during a session and help manage risk.

Integrated support service (ISS) workers completed the Domestic Abuse, Stalking, Harassment and Honor Based Violence Assessment (DASH) (71) with participants' (ex) partners. Facilitators completed the ADVANCE-D risk assessment form based on the Brief Spousal Assault Form for the Evaluation of Risk (B-SAFER) (72) with participants to assess suitability and manage and mitigate risk. Both had regular supervision and four case management meetings were held between them. The clinical risk lead provided program management fortnightly support meetings online to all professionals to ensure fidelity to the program, where ADVANCE-D content, group process, online delivery, risk and safety management were all covered. This helped facilitators feel confident and supported in their roles (35).

In order not to privilege group participants over their (ex) partners, we decided to develop a (ex)partner version of the participants' website, containing safety messages for (ex)partners. (Ex) partners could view but not interact with the ADVANCE-D website content. They were offered password-protected smartphones with 4-month mobile data (the duration of the research study), addressing the risk of their own phone activity being monitored or intercepted by the perpetrator, and allowing them to view the safety messages. During the pre-testing of ADVANCE-D, female survivors consulted about website appropriateness found the safety messages for women acceptable and welcomed the opportunity to access the website, noting that other perpetrator programs do not share content with survivors. An exit button was provided that enabled (ex)partners to exit the site immediately.

ADVANCE-D was therefore iteratively developed taking all of the above-mentioned evidence, consultation and best practice into consideration.

### 3.1.3 Overall description of ADVANCE-D, the adapted program

In the adapted program, ADVANCE-D, the content and underpinning theory remained the same as the original ADVANCE group program which targets individual risks for IPV, including substance use, poor emotional regulation, and poor stress-coping, and teaches participants how to reduce these risks by promoting self-regulation (ability to alter a response or override a thought, feeling, or impulse) (73) and personal goal setting (Figure 1). Contingency management (74) was used to enhance engagement and attendance, building on the "Good Lives Model" (75) underpinning the intervention. Although delivered in a different format, it remained fundamentally the same in that it relied on positive therapeutic alliance, well facilitated group process and strengths-based change. ADVANCE-D comprised 32 sessions, delivered remotely by two trained facilitators over 14 weeks. It included an individual session with a facilitator to set goals, develop a personal safety plan and increase motivation; a preparatory online group to prepare participants for taking part in ADVANCE-D; six fortnightly online groups, 12 self-completed website sessions and 12 coaching calls to account for best practice in terms of monitoring and managing risk and safety and increasing skills and knowledge (Figure 2). In the 2 weeks following each group, participants would complete two practice website sessions each followed by a coaching call. Participants advised the facilitator when they were intending to complete the session so that the coaching call could be booked in to follow. The 12

weekly self-directed website sessions were guided by an online coach to recap and practice skills learned in the online group sessions. The online coach verbalized the content and the text also appeared on screen, so participants had the option to listen to the coach and/or read the text. Coaching calls were delivered by a facilitator to go over the materials in the previous group and website session, check in with the participant around their relationship and substance use, especially any change in risk, and continue to enhance motivation and revisit goals. A refresher session was offered 1 month after the last online group took place.

(Ex)partners are offered support around IPV from an ISS worker and access to the website sessions (see section 3.2). The (ex)partner's version of the website has additional information to support them to stay safe.

## 3.2 Multi-center non-randomized feasibility study with nested process evaluation

### 3.2.1 Overview of methodology

A feasibility study was conducted in substance use treatment to assess eligibility, recruitment, follow-up, adverse events and uptake rates of ADVANCE-D for participants and ISS for their (ex)partners. We also determined acceptability for participants by assessing attendance and completion rates for participants, therapeutic alliance and ratings for each website session, and multiple perspectives data (male and female participants, staff) collected via brief semi-structured interviews at up to four points in a qualitative longitudinal process evaluation (76). As program outcomes to determine preliminary efficacy, we assessed IPV perpetration by participants and experience of IPV victimization by (ex)partners at baseline and the end of the program. This mixed methods approach can help understand the intervention's implementation and outcomes over time. Ethics approval was granted by Yorkshire and The Humber-Sheffield Research Ethics Committee on January 25, 2021 (Reference: 19/YH/0445).

### 3.2.2 Participants, eligibility, and recruitment for feasibility study

We aimed to recruit 60 participants already engaged in community substance use treatment in London, the West Midlands, the South West, South Wales and Lothian (United Kingdom) (77). ADVANCE-D was offered to participants who "volunteered" for the program rather than being court-mandated to attend. Participants were screened during 06/21–11/21 for eligibility against the inclusion criteria by substance use treatment staff or researchers, first remotely and once restrictions eased, in person at substance use treatment services or online groups. Recruitment flyers were also emailed to potential participants by staff inviting them to contact researchers for information. Participants were eligible if they had perpetrated any IPV in the past 12 months assessed using the Abusive Behavior Inventory (ABI) (78) toward a female (ex)partner (i.e., scored positive to one of the 29 items) with whom they still had contact in the past 4 months and agreed to provide her contact details so that she could be invited to take part in the research by a researcher, offered support by an ISS worker and could be contacted and safeguarded if any risk relevant issues arose (79, 80). A trained facilitator then assessed the suitability

of those eligible for ADVANCE-D using an adapted version of the B-SAFER (72). Men who were assessed as low to medium risk of re-abusing partners without intervention were suitable to attend the program, while those assessed as high risk were not. Those attending a perpetrator program, who had an order preventing them from contacting their (ex)partner or where there were other safety concerns were not eligible.

After participants were recruited and had provided the contact details of their (ex)partners, researchers texted or emailed their (ex) partners with brief information about the study and then contacted them to invite them to participate in the research. They were also advised that regardless of whether they agreed to take part, they would be contacted and offered support by an ISS worker. The ISS worker also completed the DASH (71) risk assessment with (ex)partners. Support focused on the needs of the individual but could include developing a safety plan, signposting after a needs assessment and counseling. The ISS worker could also offer to support (ex)partners in viewing the website and safety messages. Potential participants were given an information sheet and the opportunity to ask any questions. Informed eConsent or written consent was required prior to conducting a baseline interview.

### 3.2.3 Data collection and outcomes

Seven researchers (five women, two men) administered quantitative questionnaires (see section 4.1.4) and conducted qualitative interviews. Only female researchers collected data from men's current or ex-partners, while both male and female researchers interviewed participants. Different researchers interviewed the male participant and (ex)partner from each dyad to ensure that no information was inadvertently shared (81). The qualitative interviews with facilitators and ISS workers were conducted by a researcher not responsible for managing that research site to avoid bias. All interviews were conducted by telephone or videocall.

Changes in outcomes for participants and their (ex)partners were evaluated pre- and post the ADVANCE-D program. Only details of IPV and therapeutic alliance measures are presented in this manuscript. Incidents of IPV were not reported to the police by researchers. If severe IPV was reported [i.e., behaviors associated with a higher likelihood of a lethal outcome as defined by the Danger Assessment (82) including burning, punching, strangulation, or sexual violence], researchers enacted their duty of care by reporting such incidents to substance use treatment service or the ISS staff who made further decisions to report these incidents to police or social services to deliver supportive services based on services' safeguarding protocols and legal requirements. Participants were advised of these limitations to confidentiality during the consent process, including a verbal and written explanation of this in the participant information sheet. Details of the full study methods are described elsewhere (76).

Intimate partner violence was assessed during the past 4 months using various measures. For participants, the 29-item ABI was administered to measure the frequency of the perpetration of physical (12 items, two of which assess sexual abuse) and psychological abuse (17 items) (78). For (ex)partners, the 25-item Abusive Behavior Inventory Revised (ABI-R) measured experiences of physical (13 items), psychological (nine items), and sexual abuse (three items) victimization (83). Items were scored from 1 (never) to 5 (very frequently), with higher subscale scores and total score indicative of greater abuse. Four adapted questions from the 24-item Revised

Controlling Behaviors Scale (CBS-R) measured the use and experience of controlling behaviors (84) (e.g., want to know where your partner went and who they spoke to when not together). Response options ranged from 0 (never) to 4 (always). Two questions from a non-validated scale on the use of technology-facilitated abuse were included (85) (e.g., "Used mobile technology to check her location"). Total scores ranged from 2 (never) to 10 (very frequently). Four questions from a non-validated scale assessed the use of children against a partner (86) (e.g., "Asked the children to report on what she is doing or where she has been"), with total scores ranging from 4 (never) to 20 (very frequently). One item enquired about the frequency of stopping/being stopped by a partner from leaving the house against their will, scored from 1 (never) to 5 (very frequently). Two questions about stalking behaviors, scoring from 1 (never) to 5 (very frequently) were included. In all cases, the higher the total score, the greater the frequency of perpetrating or experiencing the behavior.

The 12-item Working Alliance Inventory applied to Virtual and Augmented Reality (WAI-VAR) (87) and the 12-item patient version of the California Psychotherapy Alliance Scale-Short Form (CALPAS-P Short Form) (88) assessed therapeutic alliance for participants at follow-up only. With the original author's permission, we changed "virtual environment" to website in the WAI-VAR. Items on the WAI-VAR are scored from 1 (never) to 7 (always) for each subscale: Goals, Tasks, and Bonds. Total score ranges from 12 to 84, with higher scores suggesting a stronger working alliance. The CALPAS-P Short Form uses four subscales: the patient working capacity, patient commitment, working strategy consensus, and therapist understanding and involvement. Participants are asked to describe the extent to which each item describes their experience from 1 (not at all) to 7 (very much so). The total score is the mean of these four subscales.

Up to four longitudinal qualitative interviews were conducted during ADVANCE-D as part of the process evaluation to capture information about acceptability: views about the intervention, changes and impact over time for participants and their (ex)-partners, and staff's experience of delivering ADVANCE-D. The interviews corresponded with completion of 4 weeks (to explore motivation, experience of welcome to group, online group 1 and website sessions 1 and 2), 8 weeks (experience of online groups 2 and 3, and website sessions 3–6, any behavior change), 12 weeks (experience of online groups 4 and 5, and website sessions 7–10, any behavior change), and 14 weeks (experience of online group 6, and website sessions 11–12, any behavior change) of the program. Therefore, interviews were only completed with men who remained engaged in the program at these pre-defined times. Participants and (ex)partner participants were reimbursed (£10 voucher) for each questionnaire and qualitative interview (up to a total of £60 vouchers, if baseline and follow-up questionnaire and 4 qualitative interviews were completed). Participants completed a rating scale online after completion of each website session.

Summary statistics were estimated to quantify relevant feasibility and acceptability parameters. In addition, scores for IPV (ABI/ABI-R) and controlling behaviors (CBS) for the 25 participants and 11 (ex)-partners who were interviewed at baseline and end of ADVANCE-D, were regrouped into three groups—where the scores increased, decreased or stayed the same from baseline to end of ADVANCE-D. Match paired t-tests and Wilcoxon signed-rank tests were performed for IPV outcomes pre and post program where

normality could and could not be assumed, respectively. Interviews and focus groups (staff) were recorded and transcribed verbatim and patterns in themes across different participants and groups of participants were explored using the framework approach (89). Data for each time point interview and category of interviewee were merged into a single framework to enable comparison, interpretation, and synthesis of longitudinal data (90). Codes were developed and data were thematically coded. The COnsolidated criteria for REporting Qualitative research Checklist were followed during analysis (91).

# 4 Results of the multi-center study

## 4.1 Feasibility results

We determined the feasibility of delivering ADVANCE-D by assessing eligibility, recruitment, follow-up, adverse events, and uptake rates [of ADVANCE-D for participants and ISS for (ex)partners]. One hundred and twenty-five men were screened for eligibility, 69 of whom met criteria for inclusion in the study (55.2%). A B-SAFER risk assessment was completed with 57 of the 69 eligible men (82.6%), of whom 54 were suitable. Forty-five participants were recruited from seven community substance use treatment services in England (London $n = 3$, the West Midlands $n = 1$, and the South West $n = 1$), Wales (South Wales $n = 1$), and Scotland (Lothian $n = 1$). Twenty-one female current or ex-partners were recruited. Screening, recruitment, and follow-up of participants and their (ex)partners are described in more detail in Figures 3, 4. The reasons men were not eligible to participate are presented in Figure 3 and the reasons their (ex)partners did not participate in the research are detailed in Figure 4.

Table 1 presents the characteristics of male participants and their (ex)partners. Table 2 describes the feasibility parameters for participants and their (ex)partners. Of the 45 participants recruited, 22 were interviewed qualitatively at least once about their experiences of taking part in ADVANCE-D: four were interviewed once, 10 were interviewed twice, six were interviewed three times, and two were interviewed four times. Of the 21 (ex)partners recruited, 11 were interviewed qualitatively: eight were interviewed once, and three were interviewed twice. All 12 facilitators (three were interviewed once, eight were interviewed twice, and one was interviewed three times) and seven ISS workers (four were interviewed once, three were interviewed twice) were interviewed.

Forty participants were offered ADVANCE-D: 16 from London, nine from the South West, six from the West Midlands, five from Lothian and four from South Wales. Five of the 45 participants recruited were not offered ADVANCE-D as two were no longer eligible, two were withdrawn and contact was lost with one man prior to the program starting Six groups were delivered with an average of 6.8 men per group (range 4–9), one of which comprised participants from two different substance use treatment services (Lothian and South Wales). At the end of the program, a structured questionnaire was administered by researchers to 55.6% (25/45) of participants and 52.4% of their (ex)partners (11/21). Three severe adverse events were identified but found to be unrelated to the study.
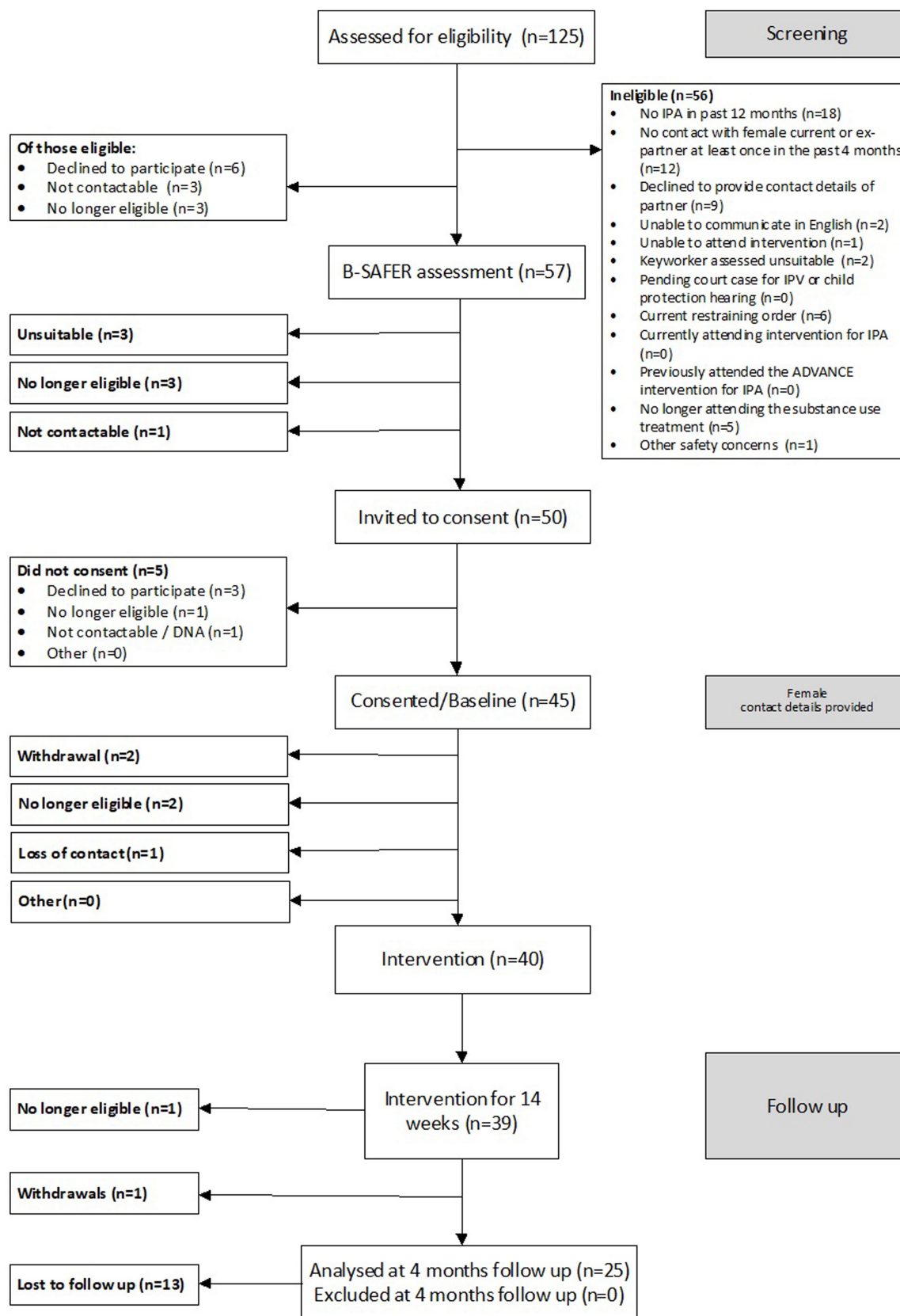
FIGURE 3
CONSORT diagram for male participants in the ADVANCE-D non-randomized feasibility study.

**FIGURE 4**
CONSORT diagram for female participants in the ADVANCE-D non-randomized feasibility study.
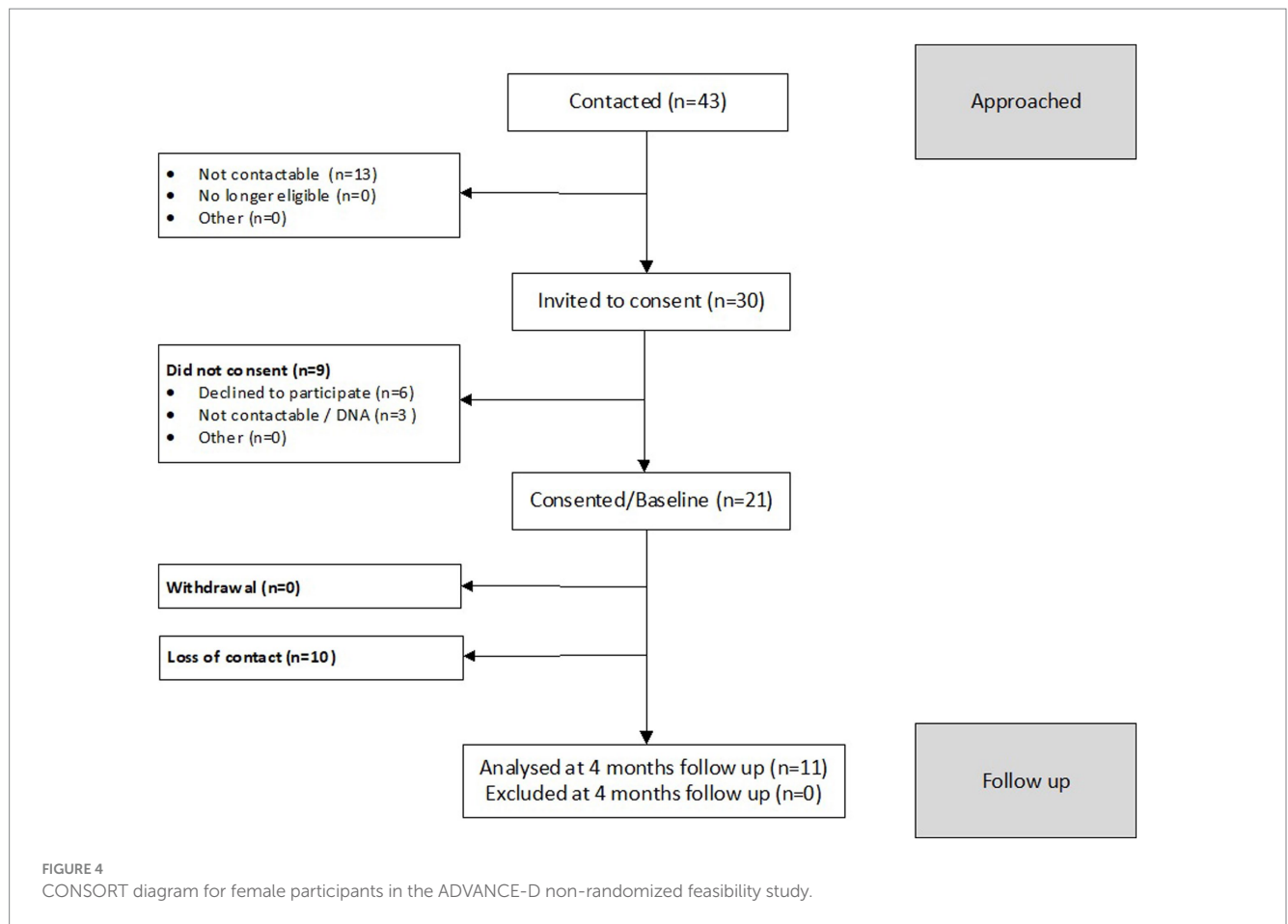
## 4.2 Acceptability results

We determined acceptability by assessing attendance and completion rates for participants, therapeutic alliance and ratings for each website session, and multiple perspectives qualitative data.

Attendance varied by site and by type of session, with group sessions having the highest attendance (Table 3). On average, participants attended 11.4 (SD 9.1) of the 32 sessions ($n = 40$ participants). Of all sessions (goal setting session, "welcome" online preparation group session and six online group sessions, 12 website sessions and 12 coaching calls) offered, 46.8% (455/973) were attended (if participants had withdrawn/been discharged, or if the session was not delivered by staff, it was considered the session was not offered) (Table 3). One-month post-intervention, 30 of the 40 participants (75%) offered ADVANCE-D were invited to attend the refresher session; 11 (37%) of whom did so. The refresher session was not offered for the following reasons: participant withdrew ($n = 1$), participant no longer continuing with study intervention ($n = 2$), and site no longer delivering intervention ($n = 7$). While personal characteristics play a role in attendance, some contextual factors may have also had an impact. The delivery of ADVANCE-D progressed successfully in South West and Lothian/South Wales with good attendance by participants. In the West Midlands, two participants were thought to have sold their tablet prior to taking part and others found it difficult to fit attending the group around work, with one participant joining the group on his lunch break by phone and

struggling to see videos. In all sites except the South West, the delivery of the six group sessions was interrupted by the Christmas break. In one of the three London sites, the second group was conducted in January. No participants joined the third group a fortnight later. This was then offered again but no one attended. The lead facilitator then went on leave for 2–3 weeks after which the group was offered again. When no one attended, it was decided to offer the remaining participant (who had been partially engaging via phone calls) an individual session but he failed to attend. One man in London site 1 had dropped out after reporting his tablet computer had been stolen. Although offered a new sim card, he proved uncontactable. In the West Midlands, due to the Christmas break and poor attendance, there was a five-week gap between online groups 2 and 3, instead of 2 weeks.

### 4.2.1 Participants' views on digitally-supported delivery

Many participants preferred the convenience of digitally-supported delivery stating accessing it from their homes and talking to facilitators by phone was easier *"makes it easier… it's not as daunting"* than traveling into a service especially for those with social anxiety or who were working: *"It's great that you have been able to run it online, because [I have] social anxiety. At the start of the course I would not really be up for face-to-face meetings, plus fears of COVID"* (ID 725). While several participants had felt *"anxious"* or *"nervous"* about attending the online group, they reported feeling able to open

**TABLE 1** Participant characteristics.

| Characteristics | | Men (*n* = 45) | Women (*n* = 21) |
|---|---|---|---|
| Age at consent | Mean (SD) | 40.0 (8.5) | 38.5 (9.7) |
| | | *n* (%) | *n* (%) |
| Ethnic group | White | 34 (75.6) | 15 (71.4) |
| | Mixed/multiple backgrounds | 4 (8.9) | 4 (19.0) |
| | Asian | 3 (6.7) | 1 (4.8) |
| | African | 3 (6.7) | 0 (0.0) |
| | Any other ethnic group | 1 (2.2) | 1 (4.8) |
| Highest qualification | No formal qualifications | 10 (22.2) | 3 (14.3) |
| | High School qualifications | 10 (22.2) | 8 (38.1) |
| | Technical/vocational qualifications | 17 (37.8) | 4 (19.0) |
| | Degree or higher degree | 4 (8.9) | 2 (9.5) |
| | Other qualifications | 4 (8.9) | 4 (19.0) |
| Employment status | Employed | 13 (28.9) | 9 (42.9) |
| | Looking after home/family | 1 (2.2) | 2 (9.5) |
| | Unemployed and looking for work | 10 (22.2) | 1 (4.8) |
| | Unable to work due to long term sickness | 19 (42.2) | 9 (42.9) |
| | Retired from paid work | 0 (0.0) | 0 (0.0) |
| | In education | 0 (0.0) | 0 (0.0) |
| | Other | 2 (4.4) | 0 (0.0) |
| Sleeping arrangements | In a hostel or supported accommodation | 1 (2.2) | 1 (4.8) |
| | Sleeping on somebody's sofa/floor | 4 (8.9) | 1 (4.8) |
| | Temporary accommodation | 3 (6.7) | 1 (4.8) |
| | Housed—in own tenancy | 20 (44.4) | 11 (52.4) |
| | Housed—in someone else's tenancy | 15 (33.3) | 4 (19.0) |
| | Other | 2 (4.4) | 3 (14.3) |
| Relationship status with (ex)partner | Together and living together | 24 (53.3) | 10 (47.6) |
| | Together but living apart | 8 (17.8) | 7 (33.3) |
| | In the process of splitting up | 1 (2.2) | 0 (0.0) |
| | The relationship has ended and living apart with no contact | 2 (4.4) | 1 (4.8) |
| | The relationship has ended and we are living apart and still have contact | 4 (8.9) | 2 (9.5) |
| | Remain friends | 2 (4.4) | 0 (0.0) |
| | Be civil for sake of children | 4 (8.9) | 1 (4.8) |
| | | mean (SD) | mean (SD) |
| Alcohol use disorders identification test score | | 16.2 (12.5) | 6.4 (8.5) |
| Drug use disorders identification test score | | 20.1 (14.0) | 7.1 (11.6) |

up, and appreciated listening to others doing the same, with participants articulating that this atmosphere felt non-judgmental, reduced shame and felt cathartic. Some stated they would have preferred an in-person group: "*I prefer face to face…you are a little bit more engaged*" (ID 401). Overall, participants reported good group dynamics. Most said it was "*good to hear other people in your position*" and that this made them feel they were "*not the only person in the situation*" (ID 206). Perceptions of group dynamics were linked to group size. In larger groups some participants found it difficult to

interject finding it hard to know if they were talking too much as "*it's a little bit harder to read the room 'cos everyone's* [*online*]," (ID 401). However, when there were few participants in groups, participants felt they were "*not getting any input* (from others)" (ID 131). The group that included participants from two different areas and services (South Wales/Lothian), was well received and participants liked the anonymity this allowed.

For some participants, setting up the tablet to access the online groups and website sessions proved difficult and frustrating, although

TABLE 2 Feasibility estimates for male participants and (ex)-partners in the ADVANCE-D non-randomized feasibility study.

| Male participants | | | Female (ex)-partners of men in the study | | |
|---|---|---|---|---|---|
| Feasibility parameters | Proportion | Proportion % | Feasibility parameters | Proportion | Proportion % |
| Eligibility rate | 69/125 | 55.2 | - | - | - |
| Suitability rate | 47/125 | 45.6 | - | - | - |
| Recruitment rate | 45/69 | 65.2 | Recruitment rate | 21/43* | 48.8 |
| ADVANCE-D uptake (attended at least one session) | 39/40 | 86.7 | ISS support uptake | 13/15 | 86.7 |
| Follow-up rate | 25/45 | 55.6 | Follow-up rate | 11/21 | 52.4 |

*Only 43 (ex)partners were contacted as we were aware at that time that two men would not be not offered ADVANCE-D.

participants reported receiving timely online technical support from a researcher who resolved issues quickly.

Participants appreciated the expertise of staff in facilitating groups, describing facilitators who made the group feel "safe" and that they felt included: "*They've been hosted really well. There were no disagreements between the guys…When talking about such a sensitive subject, you might expect more reactions and whatnot, but you guys obviously brought a vibe that meant that that wasn't really a thing… which is good… it flowed really well. Making it a safe space.*" Table 4 demonstrates that at the end of ADVANCE-D participants scored therapeutic and working alliance high.

Participants were asked to rate each website session after completion from 1 (strongly disagree) to 7 (strongly agree). Overall, participants found the website easy to use (mean 5.8; SD 1.7); understood each session's purpose (mean 6.2; SD 1.1); increased their knowledge and skills about topics covered in each session (mean 5.9; SD 1.3); and were able to concentrate (mean 5.8; SD 1.4). Participants were generally positive about the website: "*It was great. It was easy to use. I was impressed. It was better than I expected*" (ID 410) with "*very valid and great content*" (P415). They found the website sessions reinforced what they had learnt in the group sessions and vice versa and they appreciated the opportunity to work through them in their own time: "*When you do the session by yourself online after the group, I find that l helpful in a different way… you talk about stuff in the group and then you go and do the online session and then that's what I sit down with the notebook and make notes. They work very well together*" (ID 411). While some participants thought having an online coach was "*better…to actually see a face, a person talking*" others felt that listening to him "*takes too long, the avatar talking. I just read through the thing and get it done*" (ID 402), "*I did not like listening to him talk to me so I had to mute him off all the time and read it myself*" (ID 415).

### 4.2.2 Facilitators' views on digitally-supported delivery

Most facilitators reported that issues with technology or poor Wi-Fi were disruptive to delivery of the online group. Despite technology issues affecting the ease with which people were able to engage with the groups, most facilitators reported good group dynamics; with the participants "*interact[ing] well*" (London site 1, Facilitator 1) with each other despite different personalities. In managing more difficult group dynamics, having a co-facilitator was viewed as key, because it enabled facilitators to "*take a breath*" (South Wales, Facilitator 1), during the group, or "*manage if someone was*

being disruptive or there was no talk*" (South West, Facilitator 1). In contrast, facilitators felt that delivering the group virtually might have led to groups being less "*bonded*" (London site 2, Facilitator 2 and South West, Facilitator 2), with less "*rapport*" between the participants and facilitators (West Midlands, Facilitator 2), however, these issues were helped by putting the first session aside "*for group cohesion*" (South Wales, Facilitator 1).

Delivering the group virtually was believed to make it more "accessible" (London site 3, Facilitator 1) and offered participants more "*flexibility […] to attend*" given work and other commitments (West Midlands, Facilitator 2), as well as being "*protective*" (London site 3, Facilitator 1), in giving them more space to reflect.

### 4.2.3 ISS workers' views on digitally-supported delivery

Integrated support service staff reported that (ex)partners who had requested calls were often difficult to contact and were not always in a private setting or alone when the ISS called. ISS staff found that some required a brief check-in call, while others required longer support calls: "*Of the small group there are about five* [(ex)partners to support]*, one is taking up a lot of the engagement, she finds it good to have space to talk and share her experiences. The rest it's just checking in and the others have said they do not need support [from ISS] it's just [a] check in, a 10-min call. Whereas the other one is like an hour, or if you do not stop her…2h*" (London 1, ISS). There was variability in how much ISS staff reported looking at the ADVANCE-D website. While some reported finding the website useful, reinforcing existing knowledge and a good source of "refresher" messages, others reported not looking at the website or only looking at it once.

### 4.2.4 Male participants' views on ADVANCE-D program content

Overall, participants found the content "*really good*" (ID 726). Participants found the video clips "*helpful*" especially in highlighting "*what could he* [the perpetrator] *have done better*" (ID 205): "*[the videos] are good. It makes you, like I said, see things from other angles and stuff…It sticks in your head a bit more… easier to take in*" (ID 537). Most participants found the tools useful for meeting their goals: "*It's given me the tools I need to do things a bit different, and stop things getting worse*" (ID 726). Structured time out was by far the most popular tool used with positive outcomes: "*Usually I would just storm off, grab money, just go take drugs, do whatever, but now I'll actually sit down. I'll think of the consequences of the actions before I do it. Not*

TABLE 3 Attendance at ADVANCE-D program by site.

| Site | Core sessions (individual goal setting session + 7 groups)* | | Website sessions* | | Coaching calls* | |
|---|---|---|---|---|---|---|
| | N | Attended—n (%) | N | Attended—n (%) | N | Attended—n (%) |
| London 1 | 32 | 23 (71.9) | 45 | 26 (57.8) | 48 | 21 (43.8) |
| London 2 | 29 | 14 (48.3) | 13 | 7 (53.8) | 24 | 2 (8.3) |
| London 3 | 26 | 21 (80.8) | 26 | 16 (61.5) | 31 | 5 (16.1) |
| Lothian | 39 | 29 (74.4) | 60 | 33 (55.0) | 60 | 29 (48.3) |
| South Wales | 32 | 20 (62.5) | 48 | 14 (29.2) | 48 | 4 (8.3) |
| South West | 65 | 56 (86.2) | 91 | 52 (57.1) | 93 | 57 (61.3) |
| West Midlands | 44 | 18 (40.9) | 55 | 2 (3.6) | 64 | 6 (9.4) |
| Total | 267 | 181 (67.8) | 338 | 150 (44.4) | 124 | 368 (33.7) |

*Of sessions offered.

TABLE 4 Therapeutic and working alliance scores reported by participants at the end of ADVANCE-D.

| Score | N | Mean (SD) | Median (IQR) |
|---|---|---|---|
| Working alliance inventory applied to virtual and augmented reality (WAI-VAR) score | 22 | 64.7 (18.4) | 69.5 (57.0–81.0) |
| California psychotherapy alliance scale (CALPAS) score | 25 | 5.6 (1.0) | 5.8 (4.8–6.2) |

*saying it stops me all the time doing it, but I think about what I'm going to do before I do it… It makes you actually think about everything, and about their side"* (ID 537). One participant mentioned when sending texts to an ex-partner, taking a time-out allowed him *"To take a step back, like, take a time out, whether that be just relax, take a deep breath. Think before you say…try and be a bit more reserved than just lashing out verbal abuse or written abuse. Just think, 'No, I do not have to act like that'"* (ID 415).

Group sessions ended and website sessions started with a meditative breathing exercise to calm participants' emotions and focus their attention. A few participants found them helpful and had started using them *"quite a lot"* (ID 308) to *"take a step back… once you start concentrating on your breathing, you calm down and then you could have a better approach to the way you wanna deal with things"* (ID 402).

Participants who received coaching calls appreciated the individual support provided, the opportunity for *"One-to-one was definitely, I would say, the best because you can open up more"* (ID 717), for follow-up and to ask questions about the website exercises and course content: *"Coaching calls were absolutely brilliant and when I was going through tough times, she's [the facilitator] a really good listener. She's really good at what she does. She was a great support. They reinforced a lot of the messages that we were doing in the groups, and it was real-time support with what was going on in my life, which I think is invaluable"* (ID 320).

### 4.2.5 Facilitators' views on ADVANCE-D program content

Facilitators thought the program content was *"valuable"* and *"comprehensive,"* however many found it *"unrealistic"* to cover the content in the time allocated for groups: *"Both [Facilitator 1] and I agree the content is fantastic. The level of time we are given each time is unrealistic. I do not think we can deliver all of that. But the content itself is really valuable. It is very useful. There is nothing I would want to expand further on. It was very comprehensive content"* (London site

3, Facilitator 2). While some facilitators were positive about the website content, particularly the videos which they described as *"really good"* (London 1, Facilitator 2), others described the look of the website and online coach as *"clunky"* (London 3, Facilitator 1). In addition, the challenge of getting *"[participants] to do it in the right order at the right time"* (London 2, Facilitator 2) was highlighted. Since the study the time scheduled for each group session has been increased and the platform for hosting ADVANCE-D has been changed, therefore the technical issues experienced should be reduced.

### 4.2.6 Facilitators and ISS views on risk management

Facilitators valued the *"thorough"* risk assessment at the beginning of the program.

Four case management meetings took place during each cycle of ADVANCE-D between facilitators and ISS. Where facilitators were able to meet regularly with the ISS, the information sharing that this enabled was particularly valued: *"So, it was quite interesting because we got a lot of information from the partners that we had not been provided before, as we were, kind of, going through the (risk assessment) process and things like that. So, there was information that was coming to light from the partners themselves that was quite different to the information we were getting from the men"* (South Wales, Facilitator 1). ISS staff in this site gave similar reports of a useful case management meeting: *"So we discussed the case, and I think actually they learnt a lot from me. What my women were saying about their partners, that, partners might not have been really aware and – how high risk they were. So those meetings were really useful"* (South Wales, ISS). While sharing information about risk did not always take place in formal case management meetings, facilitators and ISS staff gave examples of information sharing by email (London site 1, West Midlands). Several facilitators reported insufficient or limited communication with the ISS (London site 3). However, where a change in risk was identified or any issues were *"flagged up"* these were discussed either individually

TABLE 5 Client centered outcomes for men and their (ex)-partners' in the ADVANCE-D non-randomized feasibility studyMeasure.

| Measure | Baseline | | | Follow-up | | |
|---|---|---|---|---|---|---|
| Male participants | N | Mean (SD) | Median (IQR) | N | Mean (SD) | Median (IQR) |
| Abusive behavior inventory (ABI) (perpetration) score | 44 | 40.6 (8.9) | 38.0 (35.0–46.5) | 25 | 34.2 (6.1) | 33.0 (29.0–38.0) |
| Controlling behaviors scale (partial) score | 44 | 2.2 (2.1) | 2.0 (0.0–3.5) | 25 | 0.8 (1.3) | 0.0 (0.0–1.0) |
| Use of social media in past 4 months score | 44 | 2.8 (1.0) | 2.0 (2.0–4.0) | 25 | 2.2 (0.4) | 2.0 (2.0–2.0) |
| Locked in in the past 4 months score | 44 | 1.1 (0.4) | 1.0 (1.0–1.0) | 25 | 1.0 (0.2) | 1.0 (1.0–1.0) |
| Stalking in past 4 months score | 44 | 3.0 (1.4) | 2.0 (2.0–4.0) | 25 | 2.4 (0.9) | 2.0 (2.0–2.0) |
| Using children against partner in past 4 months score | 44 | 4.6 (3.1) | 5.0 (3.0–6.0) | 25 | 4.2 (2.2) | 5.0 (5.0–5.0) |
| Propensity for abusiveness scale (anger) | 44 | 36.2 (10.6) | 37.5 (29.0–42.5) | 25 | 30.6 (11.8) | 27.0 (24.0–40.0) |
| (Ex)partners | | | | | | |
| Revised abusive behavior inventory (ABI-R) (victimization) score | 21 | 47.7 (18.7) | 44.0 (34.0–52.0) | 11 | 38.8 (15.5) | 31.0 (27.0–51.0) |
| Controlling behaviors scale (partial) score | 21 | 3.8 (4.0) | 3.0 (1.0–5.0) | 11 | 2.6 (3.0) | 1.0 (0.0–5.0) |
| Use of social media in past 4 months score | 21 | 3.2 (1.3) | 3.0 (2.0–4.0) | 11 | 2.5 (0.8) | 2.0 (2.0–3.0) |
| Locked in in the past 4 months score | 21 | 1.1 (0.3) | 1.0 (1.0–1.0) | 11 | 1.5 (1.2) | 1.0 (1.0–1.0) |
| Stalking in past 4 months score | 21 | 3.5 (1.5) | 4.0 (2.0–4.0) | 11 | 2.3 (0.6) | 2.0 (2.0–2.0) |
| Using children against partner in past 4 months score | 21 | 4.5 (2.7) | 5.0 (5.0–6.0) | 11 | 2.4 (2.5) | 1.0 (0.0–5.0) |

or collectively between the ISS, facilitator and the ADVANCE-D clinical lead to ensure risk was appropriately managed.

## 4.3 Exploratory IPV outcomes

Baseline and follow-up measures of IPV perpetration and victimization are presented in Tables 5–7. Participants at baseline ($n = 44$) had a mean ABI perpetration score of 40.6 and a CBS-R perpetration score of 2.2. The subset of participants who remained active in the research and were assessed at follow-up ($n = 25$) had a mean ABI perpetration score of 34.2 and a mean CBS-R perpetration score of 0.8 (Table 5). Reductions in perpetration scores were reported by the 25 participants interviewed pre and post program for the following outcomes: ABI Perpetration ($p < 0.05$), Propensity for Abusiveness Scale (anger) ($p < 0.05$), Controlling Behaviors Scale (partial) (Perpetration) ($p = 0.08$), and using children against partner ($p < 0.05$) (Tables 6, 7).

(Ex)partners at baseline ($n = 21$) had a mean ABI-R victimization score of 47.7 and a mean CBS-R victimization score of 3.8. The subset of (ex)partners who remained active in the research and were assessed at follow-up ($n = 11$) had a mean ABI victimization score of 38.8 and a CBS-R victimization score of 2.6 (Table 5).Reductions in victimization scores were reported by the 11 (ex)partners interviewed pre and post program for the following outcomes: ABI Victimization ($p < 0.05$), experiencing stalking behaviors ($p < 0.05$) and (ex)partner using children against her ($p < 0.05$) (Tables 6, 7). The process

evaluation demonstrated that participants reported understanding the full range of abusive behaviors, particularly recognizing emotional and financial abuse; understanding the impact of IPV on their (ex) partners; and increasing respectful egalitarian communication, as opposed to aggressive or passive-aggressive communication. Many participants also reported examples of using their new skills to avoid being abusive. Many, but importantly not all participants and their (ex)partners reported positive behavior change in relation to the use or experience of IPV, respectively. These findings will be reported in detail elsewhere (92).

## 5 Discussion

Despite *"considerable concern about the use of 'online', 'virtual', or 'digital' programs delivered remotely"* (32), we found it was possible to adapt face-to-face content from our ADVANCE group program for digitally-supported delivery (consisting of online groups, self-completed website sessions and coaching calls) and feasible to deliver it remotely to participants receiving substance use treatment. To our knowledge this is the first evaluation of a digitally-supported perpetrator program (for men who use substances) (70, 93).

Similar to an exploratory study of an online court-mandated perpetrator program conducted pre-COVID in the United States (32), we found higher retention and attendance by participants in substance use treatment receiving ADVANCE-D remotely than our in-person ADVANCE group (26), although direct comparison with other

TABLE 6  Pre and post IPV perpetration and victimization outcomes for the 25 men and 11 (ex)-partners' where normality is assumed.

|  | N | Mean difference | 95% confidence interval | p value |
|---|---|---|---|---|
| *Participants* |  |  |  |  |
| ABI—Perpetration | 25 | 4.24 | 0.51–7.97 | 0.0277 |
| Propensity for abusiveness scale (anger) | 25 | 4.72 | 1.13–8.31 | 0.0122 |
| *(Ex)partners* |  |  |  |  |
| ABI—victimization | 11 | 10.27 | 1.51–19.03 | 0.0259 |
| Controlling behaviors scale (partial) (Victimization) score | 11 | 1.55 | −0.52-3.61 | 0.1268 |

TABLE 7  Pre and post IPV perpetration and victimization outcomes for the 25 men and 11 (ex)-partners' where normality is not assumed.

| Score | N | Positive difference (A decrease) | No difference | Negative difference (An increase) | p value |
|---|---|---|---|---|---|
| *Participants* |  |  |  |  |  |
| Controlling behaviors scale (partial) (Perpetration) | 25 | 10 | 11 | 4 | 0.0816 |
| Use of social media | 25 | 5 | 18 | 2 | 0.2050 |
| Locked in | 25 | 0 | 24 | 1 | 0.3173 |
| Stalking | 25 | 4 | 17 | 4 | 0.9608 |
| Using children against partner | 25 | 10 | 13 | 2 | 0.0141 |
| *(Ex)partners* |  |  |  |  |  |
| Use of social media— victimization | 11 | 6 | 3 | 2 | 0.1025 |
| Locked in—victimization | 11 | 1 | 8 | 2 | 0.4899 |
| Stalking—victimization | 11 | 7 | 3 | 1 | 0.0201 |
| Partner using children against her | 11 | 6 | 5 | 0 | 0.0161 |

perpetrator interventions for men who use substances, including the in-person ADVANCE, was not possible due to the heterogeneity in the duration and format of interventions. In the United States, 29 court-mandated perpetrators who used substances were allocated to a 12-session integrated individual intervention and 70% completed eight core sessions (94), compared to 68% in ADVANCE-D. In the Netherlands, 27 men attending IStop, a 16-session group perpetrator intervention for men in substance use treatment, reported that 44% completed at least 75% of sessions (defined as treatment completion), with a mean of 9/16 sessions attended (95). In ADVANCE-D, 59% of participants completed at least 75% of the eight core sessions and 47% of all 32 sessions offered were completed. Forty-four percent of ADVANCE-D website sessions offered were completed. This finding is similar to one study of 32 non-court-mandated, non-substance misusing perpetrators which found 44% completed all eight online modules and 75% completed at least half the modules (guided self-help delivered via the Internet with an identified therapist who provided support and guidance of therapeutic activities) (96). We have shown that ADVANCE-D has comparable and potentially higher engagement and retention than other community perpetrator interventions delivered in-person and online for men who use

substances, including when compared to our in-person group delivery of ADVANCE. However, we do not know how the isolating factors of COVID restrictions impacted the engagement and acceptability of ADVANCE-D.

Only 55.6% of participants and 52.4% of their (ex)partners were followed-up. Attrition is a major challenge when evaluating the effectiveness of IPV perpetrator programs (97, 98). Establishing individualized participant retention plans using various strategies to maximize retention (e.g., via phone, email, through emergency and service provider contacts) and ensuring researchers build rapport and maintain relationships for the duration of the study (e.g., same researcher completes all contacts and interviews where possible), may help to increase retention in longitudinal research with hard-to-reach participants (99). Substance use is a significant predictor of drop-out (14, 17, 100), with one trial reporting higher drop-out rates among men with alcohol abuse problems (36%) than those without (23%) (101). Research suggests around 20–80% of perpetrators drop out of programs (17, 98, 102, 103), however there is a lack of standard definition of program attrition, making cross-study comparison problematic (104). Richards et al. (104) found that 26% of perpetrators dropped out following intake assessment and did not complete any

program sessions, while a further 26% completed some program sessions prior to dropping out. They found early non-engagers were more likely to have mental health problems and engagers who then dropped out were more like to have substance use problems. Presenting findings on attrition separately for early non engagement, no shows at the first session and for those who engage then drop-out (104), may facilitate a better understanding of who the program works best for and where extra support may be needed. In our study, five men who consented did not take up the intervention: two men decided they no longer wanted to take part (with no reason given), two no longer met the inclusion criteria and one was non-contactable to complete the baseline interview. During the program delivery, four men were discharged from the substance use treatment service: two chose to discharge themselves (one of whom attended none of the intervention) and two were discharged for non-engagement with the substance use treatment service (both had attended two ADVANCE-D group sessions). While we did seek to record reasons for program non-engagement and drop-out, this was not always possible as men were not always contactable. Future studies should use administrative data (e.g., health and social care records, police and prison data) to measure program outcomes in the short, medium and long term to address the issue of attrition and attempt qualitative follow-up with those who drop out or do not engage (17). Adequately powered studies should explore whether the type and severity of IPV perpetrated or experienced predicted non-engagement and attrition in the research. Given our small sample size, it was not possible to meaningfully explore predictors of drop-out. Our study took place during Covid-19 restrictions which may have resulted in more illness among staff and clients, as well as greater pressure on staff alongside delivering ADVANCE-D which impacted the continuity of program delivery. The timing of program delivery in our study may also have contributed to non-engagement as sessions over the holiday period were delayed or not delivered to schedule. To improve continuity of program delivery, future studies should ensure the program is not scheduled to be delivered over the holiday period to try to retain men in the program. Moreover, ensuring an adequate number of facilitators are trained would avoid cancelation of sessions when facilitators are on annual leave, are sick or leave their position.

The differences in perpetration (and victimization) scores pre and post program show that some men who were followed-up had reduced their use of abusive behaviors. However, given the small sample size and non-randomized study design, we do not know if these differences are due to ADVANCE-D, time, participant factors, or chance. Moreover, the lower ABI/ABI-R mean scores at follow-up could be due to attrition by participants with high scores at baseline. Engagement and retention, while higher than other perpetrator programs for men in substance use treatment, was still fairly low overall with one group ceasing to continue due to dropouts and non-attendance. Due to study constraints, long term follow up was not possible, but is required to explore whether these findings are maintained and whether ADVANCE-D is more effective than usual treatment. More research is needed before conclusions can be made about the efficacy of ADVANCE-D. An RCT is planned for ADVANCE-D with men in probation throughout the United Kingdom which will address these concerns.

Overall, the intervention content was well-received by men and facilitators. Some men preferred digital over in-person sessions as they offered increased accessibility.

Since the feasibility study was conducted, we have twice updated the usability, look and feel of the website sessions to address the feedback provided, and to provide users with options for online coaches. Little research has explored user preferences for an online therapist/avatar's portrayed gender and ethnicity outside of the gaming context. Where we could find evidence in health or social care research, most users chose the male and female avatar that portrayed their own gender and ethnicity (105, 106). Research also found that users welcomed diverse avatars and animations (107). Disclosure of sensitive information (including drug use, sexual abuse and domestic violence victimization) was more likely when avatars appeared similar in age to participants (108). Following the feasibility study, developers have created three new avatars portraying White, Black, and South Asian ethnicities, which were selected and tested with 16 people with lived experience. The ADVANCE-D manual and website sessions will also be available in Polish, Urdu and Panjabi.

The pandemic necessitated a move from face-to-face delivery of interventions to online delivery (35, 109, 110). For online interventions, it is important that the digital literacy and digital poverty of service users is addressed to ensure the ability to engage in ADVANCE-D (64–66). While there is no review of the efficacy of online delivery of perpetrator programs during the pandemic, a review compared substance use treatment delivered using telehealth with in-person treatment during the pandemic and concluded that telehealth treatment was effective but not more effective than in-person treatment in terms of retention, therapeutic alliance, and substance use (111). A recent study with men in behavior change programs concluded that *"Websites or apps can provide a safe, private space for men to reflect on their behavior and its consequences; however, the lack of interpersonal interaction can make it challenging to balance non-judgmental engagement with accountability"* (55). ADVANCE-D addressed this concern by including coaching calls with a facilitator post-completion of each website session. However, staff need protected time to prepare, deliver and debrief after delivering group sessions and coaching calls. Supervised completion of ADVANCE-D website sessions and in-person (rather than remote) group and coaching sessions at substance use treatment services could enhance attendance, completion and engagement, and ensure adherence to all aspects of the intervention.

Integrated support for (ex)partners alongside regular case management meetings and clear and respectful information sharing protocols, are essential components of the ADVANCE and ADVANCE-D interventions. Co-training and integrity support for facilitators and ISS services is needed to build strong professional relationships across services working with participants and supporting (ex)partners.

# 6 Conclusion

Given that men who use substances are underserved in perpetrator programs and are also most likely to drop out of standard perpetrator programs (14, 23, 24), alternative approaches that address their specific needs and risks, such as ADVANCE-D are required. We were able to adapt the ADVANCE face-to-face group program to reduce IPV by men in substance use treatment for blended digitally-supported delivery based on available evidence of best practice with input from key stakeholders and people with lived experience. The results of the feasibility study showed that it was feasible to recruit, engage and follow up participants from substance use treatment to the

ADVANCE-D program with enhanced risk management practices in place for (ex)partners, and exploratory outcomes are promising. An efficacy trial of ADVANCE-D is warranted with longer-term follow-up recommended. ADVANCE-D has long-term applicability post pandemic, including in other settings. Applicability of ADVANCE-D in other settings and populations remains to be tested.

## Data availability statement

The datasets presented in this article are not readily available because all data requests should be submitted to the corresponding author for consideration. Access to anonymized data may be granted following review. Requests to access the datasets should be directed to gail.gilchrist@kcl.ac.uk.

## Ethics statement

Ethics approval was granted by Yorkshire and The Humber-Sheffield Research Ethics Committee on January 25, 2021 (Reference: 19/YH/0445). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their informed consent to participate in this study.

## Author contributions

GG was the chief investigator for the research program. EG led the adaptation of the ADVANCE Program, with support from AJ, KT, CiB, and GG. GG led the development of the study protocol and applied for ethical approval. GG, SD, AJ, JH, PR, GD, RT, KT, CPB, BL, ZZ, CaB, BC, SP, JL, CE, CiB, GF, and EG participated in the design of the study including the selection of outcome measures for the study and the recruitment procedures. GG. SD, JH, AJ, KT, GD, RT, and CPB conducted scoping reviews to provide evidence for adaptation and recruited and interviewed participants. CaB led the website design and development. BC and ZZ conducted the statistical analysis. SP and JL conducted the economic evaluation. PR and SD led the process evaluation methodology with input and analysis by JH, BL, AJ, KT, GD, RT, and CPB. GG drafted the manuscript with support from all authors who approved the final manuscript prior to submission.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The handling editor JR declared a shared affiliation with the author GG at the time of review.

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# War, forced displacement, and alcohol abuse: experiences and perceptions of war-affected south Sudanese refugee youth living in Bidibidi refugee settlement in northern Uganda

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Refugees are at high risk of alcohol abuse due to their experiences of structural, physical, sexual, and psychological violence in their countries of origin, during flight, and within host communities. Given the prolonged civil war in their country, South Sudanese have continued to flee profound forms of violence and now constitute the largest population of refugees in Uganda. However, little is known about their displacement experiences, as well as the reality of alcohol use and abuse within refugee settlements. Drawing upon the direct voices of a sample of war-affected South Sudanese young people, this article explores their experiences of forced displacement and their links to alcohol abuse, as well as their perceptions regarding appropriate alcohol treatment interventions for refugees in the camp. A total of 22 semi-structured qualitative interviews were conducted with 14 refugee youth (aged 18–25) alongside eight adult key informants who work with the youth (religious leaders, sports coaches, educators, social workers, and settlement administrators). Using thematic analysis, the study revealed a series of key themes influencing and shaping the high incidence of alcohol abuse among the youth. These included traumatic wartime and migration experiences, family separation, poor prospects, and the ubiquitous availability of alcohol in the settlement. In addition, we show how alcohol operates as a strategic tool for survival for the youth, as well as highlight how these perceptions can help to inform alcohol treatment interventions in the Bidibidi refugee settlement. To our knowledge, this is the first in-depth study of alcohol abuse among war-affected South Sudanese refugee youth in Uganda, addressing a significant gap in the current literature on war-affected youth, forced displacement, and alcohol abuse. We contend that involving youth in the design of interventions can be helpful for culturally sensitive and relevant prevention, treatment, and care in refugee settings. In addition, providing employment opportunities and meaningful engagement for growth through social participation can help to address harmful alcohol use among youth in the camps.

KEYWORDS

forced displacement, war, alcohol abuse, South Sudan, Bidibidi refugee settlement, Northern Uganda

## Introduction

According to the United Nations High Commission for Refugees (1), approximately 89.3 million people were displaced at the end of 2021. The rising numbers of global displaced populations have mainly been attributed to war, armed conflicts, and natural disasters in Afghanistan, Syria, Iran, the Middle East, Ukraine, the Democratic Republic of Congo (DRC), Central African Republic, Gaza, Israel, Somalia, and South Sudan (2). These wars have dramatically altered the lives of children, youth,[1] and families with profound physical, social, economic, political, and psychological effects. War and war-induced migration have a potent impact on children and youth. In 2017, 420 million children—nearly one in five—lived in conflict-affected areas, an increase of 30 million from the previous year (3). Children are disproportionately exposed to injuries, separation from family, and sexual exploitation, while others are recruited into armed groups. War disrupts healthy child and youth development, causes injury and illness, severs familial, social, and cultural networks, and destroys structures that provide protection and preventive care (4). In 2019, more than half of the forcibly displaced population were children (5). These sudden or protracted crises can have immediate and long-lasting implications, existing in the months, years and decades beyond the original upheaval.

Humanitarian crises such as war and violence feature prominently in the lives of displaced people, where millions of people flee their homes and become refugees. Moreover, researchers (6) have found that over 76% of those forcibly displaced experience protracted displacement, remaining stateless for extended periods. Prolonged crises may lead to negative coping strategies, including alcohol use disorder, a chronic condition. In addition, alcohol brewing and selling can often become a means of obtaining non-food items and a source of livelihood for many families in refugee camps.

Such realities involving war, migration and alcohol use are important to consider among war-affected Sudanese refugees, many of whom have endured decades of war and displacement. Since its independence in 1956, the history of Sudan – a country of 45 million people, of which more than half are children – has been plagued by political and civil strife, fragility, climate change and flooding, and persistent socio-economic crises. One of the deadliest and longest civil wars in African history, war has enveloped Sudanese history and its people. While armed violence has occurred over decades, in December 2013, a power struggle between the president of South Sudan, Salva Kiir, and his deputy, Riek Machar, broke out over an alleged coup (7, 8). Since then, there has been continued fighting and instability along tribal and ethnic lines (Nuer and Dinka), resulting in numerous killings and the displacement of over 2.2 million people (7, 8). Despite the two conflicting parties signing a peace and cease-fire agreement, armed violence in South Sudan has continued. Although many people remained internally displaced, as of January 2016, over 644,000 South Sudanese had fled to neighboring countries, including Ethiopia, Kenya, Sudan, and Uganda. While other neighboring countries have hosted South Sudanese refugees, Uganda has hosted refugees from

Sudan since 1955, ultimately leading to the establishment of refugee settlements in Adjumani, Arua, Moyo, and Koboko. Due to the rapid influx of refugees following the 2013 political violence in South Sudan, the government of Uganda established the Bidibidi refugee settlement in 2016 to host South Sudanese refugees.

At the time of this study's data collection, Bidibidi was and is still the largest refugee settlement in Uganda, with a vast coverage of 250 square miles and a population of approximately 233,959 people. South Sudanese refugees make up more than 60 percent of the total refugees in Uganda (5, 9) and, importantly, over 90 percent of the Bidibidi settlement population, with women and children contributing 85% (10). According to Uganda's government refugee response monitoring system, 24% of the Bidibidi settlement population comprises youth aged 12–24 (10, 11). The settlement has a mix of people from different South Sudanese ethnic backgrounds, including Kakwa, Kuku Bari, Dinka, Nuer, Madi and Pojulu Bari tribes and are mainly Christians (7, 11). Yumbe district, on the other hand, is predominantly occupied by Muslim locals. The district is also one of Uganda's poorest districts, with subsistence farming as the primary means of livelihood (12). The Uganda government's resettlement policies have seen refugees resettled in rural areas (13). With restrictive employment policies and poor climate conditions, most refugees do not benefit from formal employment and agriculture (12). As such, most refugees depend entirely on humanitarian relief and casual labor for everyday survival. However, some refugees who arrived with or acquired some skills through on-site training may be employed by NGOs and other partner organizations.

Studies (2, 14, 15) indicate that populations affected by forced displacement and armed conflict are at higher risk for alcohol and substance abuse. Data show that youth in the settlement have lived most of their lives as refugees (16, 17). Some are born to parents who are refugees and are thus second-generation refugees. (18, 19). Living in a community where there is very little hope and limited upward social mobility can be frustrating for many young people, potentially resulting in negative coping behaviors like alcohol abuse (20). Additionally, researchers (14, 21–24) highlight that war, trauma, and stigmatization can lead to the onset of alcohol use even in communities that once limited alcohol use. Furthermore, in their study of the lived experiences of refugee youth in Somalia, researchers (25, 26) show that refugees in Africa have directly or indirectly experienced loss and anxiety-provoking events, including torture, sexual violence, killings, and abduction, all of which increase the risk for young people to use substances including alcohol. Relatedly, researchers (27) have noted that refugee children and youth in Sabia are at increased vulnerability to harmful alcohol use.

The availability of alcoholic beverages in refugee camps has been observed among the risk factors for the harmful use of alcohol. Authors (17, 28) noted that access to cheap and readily available alcoholic beverages is a significant risk factor for the harmful use of alcohol in marginalized communities. In sub-Saharan Africa, researchers (20, 29) found local alcohol brewing in refugee settlements in Uganda, Kenya, and Ethiopia. In 2006, researchers (27) assessed substance abuse and HIV vulnerability in Kakuma refugee camp in Kenya. The same study showed that locally brewed alcohol called "Changaa" (Maize brew) and "Busae" (sorghum brew) were the most used substances.

There is growing recognition that the harmful use of alcohol has significant consequences for refugees and other displaced populations,

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1 The United Nations (UN) *Convention on the Rights of the Child* defines a child as "every human being below 18 years." The UN defines youth as "those persons between the ages of 15 and 24 years."

including the adverse effects it causes on human organs and tissue, injuries or poisoning, and potential self-harm or violence (30, 31). Alcohol also has an elevated risk of non-communicable diseases (NCDs), leading to an increasing health burden among refugees, including infectious diseases such as HIV/AIDS, tuberculosis, alcoholic liver diseases, heart diseases, strokes, cancers, and gastrointestinal diseases (32). Moreover, the harmful consumption of alcohol in refugee settlements has been associated with, but not limited to, increased domestic and family violence, risky sexual behavior, suicide, assaults, school dropout, and road accidents, alongside several health risks among young adults (20, 33). The consequences of alcohol abuse are far-reaching and range from individual health risks to implications for family, friends, and the larger society. Despite these consequences, alcoholic beverages have remained widely available in refugee settings (16, 17, 34).

Although approximately 86 percent of the world's refugee population resides in low-income and developing countries (16), few studies have explored alcohol use among refugees in the Ugandan context. Most existing literature has focused on high-income countries (17, 35, 36), and little is known about South Sudanese refugees living in northern Uganda. An important exception is a systematic review of harmful alcohol use among civilian populations affected by armed conflict in low- and middle-income countries (37). This research found a significant association between trauma exposure and harmful alcohol use among Internally Displaced Persons (IDPs) in northern Uganda. The specific type of traumatic events identified included abduction, torture, rape, and imprisonment (38).

The use of alcohol is widely recognized as having severe physical, social and health consequences. In refugee camps, harmful alcohol use can further diminish an individual's quality of life and increase morbidity and mortality rates. Existing literature highlights significant socioeconomic and health needs for refugee youth, making it crucial to investigate the intersections of forced displacement and alcohol abuse in the Bidibidi settlement, which is the goal of this paper. To our knowledge, this is the first in-depth study exploring alcohol use among war-affected South Sudan refugee youth in Uganda, addressing a significant gap in the current literature on war, forced displacement and alcohol abuse. Moreover, privileging the perspectives of young refugee youth can develop effective interventions to address alcohol use and misuse in vulnerable refugee communities. To that end, we draw on the direct voices of a sample of South Sudanese youth and key informants to explore the experiences of alcohol abuse in the context of war-related displacement.

## Methods and materials

This article is part of a more extensive qualitative study (39) that sought to gain first-hand information on forced displacement experiences and alcohol abuse among war-displaced youth. Hinged on the critical realism paradigm (40), a case study design was adopted to enable the researchers to gain broader, in-depth information along with the symbolic practices, meaningful beliefs and emotions inscribed in daily interactions. The population for this study was drawn from South Sudanese refugee youths living in the Bidibidi settlement in northern Uganda, as well as key informants who worked with them.

Ethical approvals for this study were received through the McGill University Research Ethics Board III. This study was further approved by the Office of the Prime Minister (OPM) through the Refugee Commissioner General in Uganda, and the Bidibidi refugee settlement Commandant Officer provided approval before data collection in the settlement. All the required steps were taken to ensure participants were thoroughly informed about the study objectives and the protection of the information they provided. Additionally, participation in this study was voluntary and informed consent of the study participants was sought before and during interview sessions. The first author is a trained social worker and was able to address distress directly when it arose during the interview.

To be eligible for inclusion in the study, youth (both young men and women) of South Sudanese origin were required to have lived in the Bidibidi refugee settlement for at least a year before the scheduled date of the interview. Regarding age, the youth aged between 18 and 25 years were accepted based on the majority age in Uganda. Key informants actively working with the youth in the settlement for 6 months or more by the time of data collection were eligible for selection to participate in the study.

To recruit participants, the first author worked closely with social workers from the Office of the Prime Minister (OPM) in Bidibidi Base Camp. Recruiting participants during the COVID-19 pandemic, when the data collection occurred, was a significant challenge. To overcome this, the assistance of a social worker who had existing solid relationships with the youth living in the settlement and key informants was sought. The social worker actively engaged youth who varied in age, gender, wartime experiences, and time in the camp. Given their knowledge of the youth in the camp, the social worker also helped to assess whether the youth were well enough to participate and avoided engaging youth who might be at risk of experiencing undue stress or mental health problems as a result of discussing issues related to war, migration and alcohol consumption.

In addition, the social worker shared recruitment materials with both youths and key informants and ensured that they understood the study's goals. The social worker then collected the contact details of interested participants and provided them to the researcher, who followed up. Given the violent and distressing events that these young people experienced during the war, in flight, and upon resettlement, and the sensitivity of research, the first author independently conducted an initial phone or WhatsApp screening for current distress to exclude potential participants with emotional difficulty. Only the youth who passed the phone screening and could comprehend the English language were eligible to participate in the study. To assess participants' mental health, the Refugee Health Screener RHS-15 was employed. Participants were asked the following three yes/no questions during the phone screening:

1 Are you currently receiving any professional mental health services?
2 Do you have difficulty remembering past events (Cognitive challenges)
3 Do you have sleep disturbances, feeling sad, angry, anxious, or depressed when discussing your past experiences?

Those who answered "yes" to any of the three questions were excluded from the study.

A total of 22 participants, including 14 refugee youth aged 18–25 and 8 adult key informants aged 26–65, were purposively selected for interview. A semi-structured interview guide was developed and used to collect data from the youth. Although the interview guide exposed all the youths to similar questions, non-active alcohol users were probed to provide more information on the protective mechanisms they used to avoid problems with alcohol. In contrast, active alcohol users offered more insights into the risk factors and the influence of alcohol use and abuse. A semi-structured key informant guide was developed and used to collect data from the key informants, who were community leaders (Local Council officials and law enforcement officers) and Bidibidi settlement staff members (refugee welfare council officials, social workers, sports coaches, educators, health workers, and counselors) working with the youth at the community level.

Drawing on their personal, professional, and community experiences working with the youth on diverse programs, key informants were able to provide deeper insights into the war, displacement, and alcohol use. All interviews were audio-recorded and transcribed verbatim by the first author. All identifying information shared by the participants in the audio recordings was removed during transcription. To support study participants, the social work department in the camp was available to provide debriefing support for participants. In addition to providing emotional support, the department offered various other services, including educational support, health services, and recreational services. The study participants were provided information about waiting lists and the exact nature of services. Risks to key informants and settlement staff members were minimal as they were interviewed in their professional capacities.

The interview transcripts were coded using Nvivo 12 software. Transcripts were read multiple times to draw codes related to the experiences of forcefully displaced South Sudanese youths with alcohol abuse in the Bidibidi settlement. This was followed by inductive approaches, including identifying conceptual phrases used by the participants to generate categories. A total of 32 categories were then grouped to capture the complexity and diversity of the data. Categories were then merged into 22 themes and 12 subthemes, all supported by direct quotes from individual study participants. Examples of themes and subthemes that emerged from the data included alcohol as a coping mechanism, alcohol use and cultural breakdown, and the use of alcohol as a means of livelihood and socializing. To ensure member-checking, the themes were reviewed by the local social worker and the key informants, alongside youth who did not participate in the study but had similar experiences, to verify that the emerging themes resonated with them.

There are two main limitations we note in this study. First, the study was conducted during the COVID-19 pandemic, and the restrictions could have affected other potential participants for in-person interviews. Secondly, as with all self-report data, the realities and limitations of memory and self-disclosure were not considered, although we acknowledge some of the violent and distressing events that these young people experienced during war, flight, and upon resettlement. Therefore, it is conceivable that, occasionally, some of the participants may have concealed some anxiety-provoking aspects of their stories. Lastly, this is a qualitative study with a small number of participants. Given the sample size, the findings cannot be generalized to all refugee youth living in the Bidibidi refugee settlement.

# Findings

## Table showing demographic characteristics of participants

The table above represents the demographic characteristics of 22 participants comprising 14 refugee youth aged 18–25 years and eight adult key informants aged 26–65. The youth arrived in Uganda between 2016 and 2017 following an escalated tribal conflict in South Sudan. Key informants comprised local community leaders, social workers, refugee welfare officials, community mobilizers, and religious leaders who work closely to administer and provide services for refugee youth in the Bidibidi refugee settlement (Table 1).

Drawing upon the direct voices of war-affected South Sudanese young people and adult key informants, this article presents three themes and eight subthemes that emerged from the youth and key informant interview data. These include alcohol as an anesthetic, alcohol as a booster and tool for survival, and the youth and service providers' perspectives on treatment and intervention. The subthemes that emerged include alcohol and its links to war and displacement experiences, alcohol as a means of coping with loss and separation from family, alcohol as a means of dealing with cultural breakdown and fragmentation, alcohol as a means of coping with perceived poor prospects among the youth, alcohol as a source of economic survival, alcohol as a tool for social interaction and relationship building, alcohol as a means to cope with stress and loneliness, and alcohol as a perceived cure for the COVID-19 virus. Participants underscored the widespread production of local brewing in the settlement and observed that people were increasing their alcohol consumption in the camp. Participants reported that in 2016, when they came to the camp, there was zero alcohol production in the settlement. However, they noted that people now tended to drink more, the longer living in the camp, and as their individual and collective hardships continued. Participants perceived that as the crisis in South Sudan has become protracted – "a marathon rather than a sprint" – alcohol brewing and consumption has also become chronic and used not only as a coping mechanism but also as a source of livelihood for displaced families engaged in the brewing business. The following section addresses these multiple themes in greater detail.

## Alcohol as an anesthesia

Participants often narrated that youth drank alcohol as a negative coping strategy to deal with the crisis and its related grief, sorrow, hardship, and loss. Participants reported that some youth consumed alcohol to numb and forget the psychological stress and trauma, fear, experiences of war and their prolonged stay in the refugee settlement.

### Alcohol and its link to war and displacement experiences

Both groups of participants reported that many youth in the settlement were using alcohol to forget about past wartime traumatic memories in South Sudan. The violence that participants and their family members had endured in South Sudan, as well as during the migration journey, was often linked to alcohol consumption. Alcohol

TABLE 1 Demographic characteristics of the study participants.

| Participants | Age in years | Religion | Education status | Role with refugees | Country of origin |
|---|---|---|---|---|---|
| Refugee Youth Male 1 | 25 | Anglican | Primary Education | Volunteer | South Sudan |
| Refugee Youth Male 2 | 24 | Anglican | University education | Community Volunteer | South Sudan |
| Refugee Youth Male 3 | 25 | Catholic | Secondary Education | Not in School | South Sudan |
| Refugee Youth Male 4 | 25 | Catholic | Primary Education | Not in School | South Sudan |
| Refugee Youth Male 5 | 25 | Catholic | Secondary Education | Not in School | South Sudan |
| Refugee Youth Male 6 | 23 | Catholic | Secondary Education | Schooling | South Sudan |
| Refugee Youth Male 7 | 22 | Muslim | Secondary Education | Schooling | South Sudan |
| Refugee Youth Male 8 | 24 | Anglican | Secondary Education | Not in School | South Sudan |
| Refugee Youth Female 1 | 24 | Catholic | Secondary Education | Community Volunteer | South Sudan |
| Refugee Youth Female 2 | 19 | Anglican | Secondary Education | Schooling | South Sudan |
| Refugee Youth Female 3 | 21 | Catholic | Secondary Education | Schooling | South Sudan |
| Refugee Youth Female 4 | 19 | Catholic | Primary Education | Schooling | South Sudan |
| Refugee Youth Female 5 | 22 | Muslim | Primary Education | Not in School | South Sudan |
| Refugee Youth Female 6 | 23 | Anglican | Primary Education | Schooling | South Sudan |
| Key Informant Male 1 | 34 | Anglican | Diploma | Religious Leader | South Sudan |
| Key Informant Male 2 | 43 | Catholic | Diploma | Refugee Welfare Official | South Sudan |
| Key Informant Female 1 | 26 | Born Again | Primary Education | Community Mobilizer | South Sudan |
| Key Informant Male 3 | 45 | Born Again | Secondary Education | Community Leader | South Sudan |
| Key Informant Male 4 | 28 | Catholic | University Education | Social Worker | Uganda |
| Key Informant Male 5 | 65 | Muslim | Primary Education | Community Leader | Uganda |
| Key Informant Male 6 | 30 | Catholic | University Education | Social Worker | Uganda |
| Key Informant Male 7 | 41 | Muslim | Diploma | Refugee Welfare Official | South Sudan |

was reportedly used as a coping mechanism in the aftermath of such profound crises and hardships. As this youth participant explained:

> … killing in South Sudan was too much, and we decided to leave with my brother. We suffered from hunger on the road, and even water was a problem. On our way, my brother was shot dead. So, when I got here, I found life was difficult and it was my brother who used to help me. By the time we came here, there was nothing I could get, and I started thinking of my brother. I said, if my brother could be there, then I should not have this difficult life. So, because my brother was killed, it gave me too much stress, and I started drinking alcohol. [Refugee Youth Male 8].

These key informants shared their perspectives on the link between forced migration, violence, and alcohol consumption among the youth:

> … most of these children you see around are fostered children. Many are UAM they are unaccompanied. UAM means unaccompanied minors. Those are children who ran when they lost their relatives when they lost their parents, making them flee because of fear of being also killed as it happened to others. So those are the conditions that made people come. You see some of the family members are being killed, then you see all your properties are being destroyed or collected, and you remain there alone. Automatically, to stop thinking about that, they will be forced to drink alcohol. [Key Informant Male 2]

> …most of the young people from the refugee side have involved themselves in too much drinking due to the following reasons. One, the majority of our children have not gone to school. There is a high rate of illiteracy, OK? This has left many of our youths unable to make creative minds and be innovative in thinking about what they can do to make themselves sustainable or reliable. Then two, trauma, you know, when people were running, people lost a lot of their properties, and of course, when you are a visitor in another land, you will never be the same. For quite a period, you will be thinking about what you have been having, and you will be thinking about how you will recover now. You will get confused and feel a lot when you see the limited opportunity. [Key Informant Male 3].

## Alcohol as a means of coping with loss and separation from parents/guardians

Participants reported that the stress from separation was a contributing factor to alcohol abuse after resettlement in Bidibidi. We observed that many young people lived in the settlement without their parents. When asked about the whereabouts of their parents, some youth reported that they came to the Bidibidi settlement without any parent or guardian. In other cases, the youth said their parents had returned to South Sudan and left them in the settlement. Participants linked their loss of family and lack of parents and guardians to alcohol consumption:

*But there are also some youth, let's say, who are orphans; they don't have someone like a relative in the camp; others left their parents in South Sudan, and others are total orphans; they do not have any parents. So, because of hardships, instead of focusing on what will change their lives, they will just get engaged in drinking alcohol because they think it is the last option for them to do.* [Refugee Youth Female 2].

*Yes, I even have one of my friends. We reached out to him as a team and tried to talk to him. The question was, he told us we should not waste our own time because of him. He said he has lost many things in his life; he wants to take alcohol so that he can also lose his life like he has been losing his people. Then we tried to tell him that maybe he would be the root of his family. So, we try to advise these youth. [Some] understand while others do not understand. We have one of our friends, also, who has lost both parents on the road to Uganda. And since we came here, all the time he was taking alcohol.* [Refugee Youth Male 6].

Participants asserted that alcohol abuse was not only associated with the lack of parents/guardians but also the loss of parental guidance and socio-economic protection within the settlement itself. The parents' failure to provide for the family, particularly for the youth, reportedly resulted in an expectation-reality gap leading to socio-economic loss and family breakdown. As this key informant explained:

*… [Fathers] are supposed to head the family, but here is a situation where these men cannot provide anymore. Their hands are tied up; almost everything has failed for now. I should say the economic aspect traumatizes them, so alcohol is used so that the wives, children, or relatives cannot ask them. They will know this is now a drunkard, So one factor is they are doing it to dodge responsibilities at home, which is true.* [Key Informant Male 6].

## Alcohol as a means of coping with cultural fragmentation & breakdown

Many participants described in depth how enduring war in South Sudan, flight across the border into Uganda, and their protracted stay in the Bidibidi settlement had disrupted and fractured their sense of culture, identity, and traditional ways of living. The South Sudanese refugees had lost not only family members, relatives, and neighbors but also those who fled the South Sudanese war at a young age and were growing up in the settlement reported losing their traditional South Sudanese culture. These youth explained the link between cultural loss and fragmentation with alcohol use and abuse:

*… as people were fleeing the conflicts from South Sudan to other places, people were mixing and copying from each other's culture. Here in the settlement, we have many tribes, many of whom are alcohol prone even when they were in South Sudan before the war. They also brought that habit here in the settlement.* [Refugee Youth Male 7]

*… in the Kuku culture, the child becomes an adult at 20,21, or 22 years or more. If the child at this age is caught drinking alcohol, they*

*will be seriously punished by their parents or even the community. But today, as we are speaking here in the settlement, we see our children taking alcohol even at the age of 18 years because they were told that at that age, they are mature enough to do whatever they want. Living in the settlement has destroyed our children. If we had brought up our children according to our culture, we could have well-behaved children.* [Key Informant Male 3]

Coming to the Bidibidi refugee settlement in Uganda meant adapting to a new context and learning a new language and culture, all the while facing long-term unemployment. Many participants articulated that although they had rebuilt some sense of community, most youth reported feeling broken, fractured, and lost. This youth describes how the breakdown of culture is both a result of war-induced migration as well as a key component in the inability to prevent or address alcohol abuse:

*When we were in South Sudan, it was the elders who were drinking alcohol and beer. Traditionally, if a child is caught drinking alcohol, they will be seriously beaten by the parents. And if, as a young youth, you taste the alcohol, you will be afraid because you are aware that you could be seriously punished. I know not all are drinking alcohol, but settlement has destroyed our culture, and no one cares. If we had grown up our children according to our culture, we could have well-behaved children and not drink too much like this.* [Key Informant Male 4].

Both key informants and youth reported that the problems related to alcohol use and abuse, such as family neglect, family violence, suicide, assaults, and sexual abuse in the Bidibidi settlement, affected the whole community of South Sudanese refugees in the camp.

*… once the youth get involved in drinking alcohol, they lose the ability of responsibility and honesty and become careless with their lives. They get involved in unprotected sexual affairs under the influence of alcohol and intoxication. The other significant consequence is suicidal acts. We have cases of attempted suicide, and we have successful suicide, which has happened here in this settlement due to alcoholism. Some people have died after repeated abuse of alcohol in the settlement here* (Key Informant Male 1).

This young woman described the gendered realities, implications, and insecurity of life in the camp and the links to alcohol:

*… And once you are caught alone, maybe you are two, and for those boys, they are many in a group, they may turn to rape you and, at times, beat you up. That is the problem we have seen with alcohol; it is affecting everyone, even young children below 18 years of age* (Refugee Youth Female 3).

## Alcohol as a means of coping with perceived poor future prospects

Youths in the Bidibidi settlement reported using alcohol as a result of boredom, isolation, and hopelessness in the settlement. For the older youths, there were few educational and employment opportunities in the settlement, and the youth reported spending

much of their time simply hanging out in the trading centers with nothing to do other than playing cards and drinking alcohol. Participants said that the war and resulting displacement fostered feelings of powerlessness and hopelessness, which reportedly had a critical impact on alcohol use. This key informant explained:

> … when people were running, people lost a lot of their property, and of course, when you are a visitor in another land, you will never be the same. For quite a period, you will be thinking about what you have been having, and you will be thinking about how you will recover now when you see the limited opportunity; that is when you will get confused, and you will think a lot. For you to reduce your thinking, you will have to drink [alcohol] [Key Informant Male 2].

## Alcohol as a means to cope with stress and loneliness

Participants maintained that past wartime experiences and associated memories did not solely cause alcohol use but also the settlement situation itself, which reportedly caused distress, boredom, and loneliness among the youth:

> … actually, spending a week here is not something easy because we, the youth, are idle, and there is nothing that we can do. You find that if the day starts like this, we shall just be loitering around, playing cards, drinking alcohol, and playing dominos (gaming machines), and there is no other help we can get from that. And life is not all that fine [Refugee Youth Male 8].

Participants often reported increased stress related to their education, employment, acculturation, weather conditions, housing, food, language, and health in the camp. Participants reported that disruptions in resettlement and trouble connecting with their host community invoked feelings of loneliness, making many young people feel socially isolated and marginalized:

> Well, at first, it was hard because people in this community were insulting us by saying, you South Sudanese can not stay on our land and destroy our trees because there were very many South Sudanese coming in Uganda. I felt that I was not welcome, I felt like I had nowhere to go, my life was ruined, and I did not know why I was still living. [Key Informant Male 1].

Alcohol use and abuse were perceived as a way of escaping, dealing, or coping with the multiple and complex stress-related events that occurred in the settlement.

> I want to say that the rate of youth taking alcohol is high, particularly in my zone. One could be due to a lack of parental guidance. You know, most of the people who are here in the settlement are women and children. Most men were left behind for one reason or the other. Then you know these women are regarded as weak, and these youths tend not to respect them, leaving a gap for these people. Then, two, it could be unemployment. Some youths have gone to school, and here they are redundant. Some have documents, and getting a job here is very difficult, which also contributes to the use of alcohol. The other could be peer group influence; you know, in this

> world, we have good and bad friends, so that one could contribute. [Key Informant Male 3]

## Alcohol as a booster and tool for survival

Participants reported that due to the prolonged crisis and extended stay in the settlement, some people turn to alcohol brewing as a business. Participants also reported that young people drink alcohol to get energy, boost their confidence, feel more positive or enjoy the company of friends. Both sets of participants reported limited formal employment opportunities in the camps, and the soils do not support crop farming. According to participants, they were brewing alcohol thus provided a means of livelihood and economic survival, a means of socializing and building relationships, a way to contend with stress and loneliness, as well as a "medicine" for preventing or curing COVID-19. This section addresses these themes in greater detail.

### Alcohol as a tool for economic survival

Participants described that some youth in the settlement were engaged in local alcohol [Nguli] brewing as a source of livelihood. These youth describe locally-made alcohol, its accessibility, and its use as a form of economic survival:

> As we receive food, we have been selling it to buy charcoal, pay some fees for children in school such as development fees, and buy books and soap, but as you know, the food that is left is little, and hunger, therefore, affects us ….so we starve until the next food is distributed … But now we brew this alcohol, and we sell this alcohol to buy what is not provided to us like soap, milk for the children. [Refugee Youth Female 3]

> Locally, here we have what they call "Nguli," made from cassava and yeast, made from millet or sorghum. It is a bit risky but locally made here. It is the most common and the cheapest. But we also have others which are factory made, there is one called Coke Gin, Vodka, Cheza, Ola, the Best wine, Jonnies is also cheap, and these people [youth] want to consume alcohol that makes them drunk as soon as possible or as quickly as possible. [Refugee Youth Female1].

### Alcohol as a tool for social interaction & relationship building

Alcohol use and abuse among the youth were perceived as a gateway and facilitator of social interactions and friendships with peers. Many young people articulated that sharing alcohol was not only a way of having fun with friends but also helped to create relaxed environments to find support in their shared experiences. Drinking alcohol was associated with social experiences and a means to help build and strengthen new friendships. This youth explained the link between moderate alcohol consumption and family and community building in South Sudan:

> In South Sudan, alcohol used to be consumed by elders around evening hours. Alcohol was consumed in moderation and for

*socialization among family members, relatives, and friends.* [Refugee Youth Female 1]

Shared beliefs, norms, and expectations also played a significant influence on alcohol use and abuse among young people in the settlement, with some participants reporting that declining to share alcohol when offered by a friend was considered anti-social and inappropriate:

> *You know how people are working. I am a construction worker, and you spend the whole day standing, and by the time you return home, you are already tired and feeling pain. If you call your friends, they will tell you they want something to energize them. Of course, when they call you to come to the trading center, they will buy some alcohol, and you can not refuse to take it because they feel bad. It is not good to refuse when a friend buys you a drink.* [Refugee Youth Male 5]

## Alcohol as a perceived "cure" for the COVID-19 virus

Many participants perceived alcohol as serving a medicinal purpose and that alcohol had a functional use. The participants mentioned that alcohol was good for their health – even acting as a cure for the COVID-19 virus. Some young people reported that they drank alcohol to address the boredom of the lockdown and to "sanitize" their bodies from COVID-19:

> *Now, they are increasing, and because of COVID-19, the cases are growing too much; the students even start drinking alcohol because of this lockdown. So, because of this lockdown, there is no school, and others are saying let us drink this alcohol to sanitize our bodies. They say that alcohol kills the COVID-19 virus.* [Refugee Youth Female 6]

> *Then, due to this issue of COVID-19, it is difficult since we have been locked up and there is no school; we are finding life difficult. That is why most of the youth ended up giving up and saying if this is their life, they better do what they can do. That is why most of them end up drinking alcohol, and some of them are even smoking opium and cigarettes.* [Refugee Youth Male 9]

## Youth and service providers' perspectives on treatment and intervention

This study explored youth perspectives on the availability and accessibility to alcohol use services and intervention programs directed to the youths in the Bidibidi refugee settlement. Both youth and key informants often reported that there is no specially trained personnel in any of the partner organizations to coordinate or implement services related to alcohol use among the youth in the Bidibidi settlement. Similarly, both sets of participants also reported that there are no specially designed programmes and interventions to manage the health and social consequences of harmful alcohol use among abusers and those indirectly affected in the Bidibidi settlement:

> *Specifically, services targeting youth who are drinking alcohol are not there; we don't have it, but it is general protection. We have IRC (International Rescue Committee), World Vision, OPM, and UNHCR, where alcohol is incorporated, but as a specific organization, looking into youth who are engaged in drug abuse is not there. In the settlement here, we used to have CARITAS. CARITAS Uganda used to come to the community for meetings with parents and children, and even at schools, they could visit and advise children on the dangers of alcohol. Still, since they left many years ago, no partners have talked to the youth or counselling them that they can do this and that.* [Key Informant Male 2]

The exception mentioned was for emergencies, especially where the individual is experiencing a life-threatening condition due to alcohol. Both youth and key informants highlighted that when an individual had a health crisis or complication due to alcohol abuse, it was commonly family members, relatives, and, at times, significant others who attempted to seek help from the Bidibidi Health Centre. Participants highlighted that there were no designed rehabilitation programmes or services for alcohol-dependent youth:

> *Let me say no organization is working to stop alcohol. But here, let me say that RWCs (Refugee Welfare Committees) are the ones who help the children during emergencies. If they see the way youth are behaving, others who would fight, they assault themselves, or when the person collapses, they will take them to the health center. But it is the family members and friends, let me say, peers, help the youth many times.* [Key Informant Female 1]

Both sets of participants reported that alcohol use campaigns were not conducted regularly, consistently or in a coordinated manner. They also mentioned that there are few materials available to the youth on alcohol use-specific issues. Refugee youth also reported that they struggle with stigma from self, family, friends, the host community, and health care systems. The youth perceived that given that the majority of host communities belonged to the Muslim faith, they condemned alcohol use. Participants reported that the stigmatization from the host community further destabilized their lives, as they felt shame to seek help at health facilities outside the settlement. These participants explained:

> *You see, I cannot go to the hospital for treatment because people will laugh at me; alcohol is not sickness, and they will say, look at this drunkard because most people in Bidibidi [host community] are Muslims. I feel ashamed to go to the clinic in the host community.* [Refugee Youth Male 1]

> *One is that at times the youths don't attend our meetings. They are like it is not their concern now, and we blame them. They fear attending community health meetings and even going to the health center. Then two, especially those schoolgoers, don't have time to attend and meet us, but we also have a strategy in our simple leadership structure. We have a leader for the youths from various levels, and at times, when we organize a meeting, we spearhead these youth leaders and empower them to talk to them.* [Key Informant Male 4]

## Discussion

### Alcohol use/misuse among war-affected youth

Our findings suggest that alcohol use and abuse among South Sudanese refugee youth are shaped by a multitude of complex factors related to the war in South Sudan. Interviews uncovered that alcohol consumption is an essential strategy for the youth to attempt to forget about the war and its related grief, sorrow, stress, loss, and the multiple hardships attributed to prolonged stay in the camp. Alcohol consumption was also used as a form of anesthetic to cope with traumatic wartime experiences and the challenges of flight and resettlement. These experiences include mass and indiscriminate killings, torture, abduction, burning of houses, looting and destruction of property and violence. Findings align with existing studies that have noted the use of alcohol as a coping strategy to deal with stress (21, 37, 41, 42).

The findings also indicate that war trauma and forced displacement exacerbated vulnerability to harmful alcohol use among the young people in the settlement. These findings are consistent with the existing literature (36, 37) that has found that continuous exposure to traumatic events is associated with alcohol use. Additionally, researchers (35, 43–45) have illuminated that refugees who experience war or conflict-related trauma are at greater risk for poor mental health and alcohol abuse. This study has revealed that some youth consume alcohol to cope with and forget war-related atrocities. Findings also show that the youth drink alcohol to cope with the daily frustration from settlement challenges such as illness and inadequate basic needs like food, shelter, and education, but also to "fit in" with their peers who drink alcohol. This is in line with other research on Somali refugees (17) that found that young people use substances such as Khat, Tobacco and alcohol as an essential way to build social bonds and as a representation of their anger, frustration, and resistance to failed protection from the Kenyan and Somali communities.

The findings also demonstrate that alcohol is used as a booster and tool for survival in crises. Alcohol brewing serves as a source of livelihood for many families in the settlement. Some women brew and sell alcohol to buy non-food items such as clothes and pay hospital bills and school fees for their children. Alcohol is also associated with socialization, pleasure, and fun among the youth. These experiences are centered around bars and drinking outlets in the trading centers within the settlement. This is similar to a study (14) among Congolese Babembe male refugees resettled in camps.

According to both sets of participants, protracted stay in confined refugee settlement conditions and the realities of boredom, loneliness, and poor prospects contributed to alcohol abuse. In addition, participants reported extremely stressful and prolonged settlement issues such as lack of employment, lack of education, and struggles associated with acculturation, extreme weather conditions, inadequate housing, food insecurity, and language barriers. These findings support previous evidence that experiences of severe resettlement challenges may predispose young people with refugee backgrounds to a wide range of poor health and social behavioral outcomes (19, 43). Additionally, researchers (9) have reported the association between a prolonged stay in harsh refugee camp settings and substance abuse among Congolese refugees.

Findings also reveal the local brewing of alcohol, alongside the availability of numerous drinking establishments in the Bidibidi settlement. Similarly, researchers (16, 17, 37) have noted that refugee communities are becoming increasingly affected by home-brewed alcohol consumption. Additionally, research (19, 43) has illuminated the prevalence of a culture of alcohol consumption in refugee camps. Moreover, as found in this study, alcohol use and its associated disorders can be highly stigmatizing, whereby moral deficiency or lack of self-control and willpower are attributed to affected individuals. This challenges youth seeking help, ultimately affecting treatment-seeking and recovery efforts. In a similar vein, in a study of Karen refugees, researchers (22) established that rebuilding community structures and bonds destroyed by conflict and displacement were essential ingredients to address harmful alcohol use in a refugee setting. Thus, building a supportive network of peers is necessary to support access to services in refugee settlement contexts and reduce shame and stigma.

Participants indicated that alcohol use and abuse were linked to loss and cultural breakdown. Research has underscored that refugee children are at substantially higher risk than the general population for a variety of specific psychiatric disorders related to their exposure to war, violence, torture, and forced migration (46). Moreover, children who are separated from their families pre- or postmigration are said to be at increased risk of psychological and social challenges (47). In this sense, the mental health of refugees is powerfully influenced by war-related violence and loss combined with the conditions they encounter in route to and within their host contexts. It is thus not particularly surprising that youth in the Bidibidi settlement are struggling with issues of loss, separation, and the fallout of war-related violence. It does, however, highlight the need for more excellent policy and service attention to provide those living in refugee camps with greater access to vital mental health support to address the violence and upheaval that they have endured.

### Implications for intervention services, policy and future research

In the absence of prior published studies on the experiences and perceptions of war and forced displacement realities of alcohol abuse among South Sudan refugees in Uganda, this study provides a baseline for further research and contributes to policy and practice knowledge. As in many African countries, alcohol use is part of many cultural, religious, and social practices in Uganda (48). Alcohol consumption is a common characteristic of Ugandan social life among the general population (48, 49). For South Sudanese refugee youth in northern Uganda, it is thus reasonable to argue that drinking alcohol is part of the acculturation process (14, 19). However, harmful alcohol use can lead to short-term and long-term negative consequences for war-affected refugee youth, making it essential to prioritize policy attention. To reduce alcohol use and abuse in refugee settings, cost-effective policy options such as regulating alcohol availability, restricting public drinking and regulating alcohol advertisements in refugee camps can be implemented (50). Age restrictions and greater taxation of alcohol are also effective measures to curtail harmful alcohol use (51).

Most approaches to refugee psychosocial support, including alcohol use services and treatment options, have been dominated by perspectives from the Global North, which center on individualistic approaches to practice, intervention, and treatment (52). Additionally, responses and services may rely on a biomedical model, overemphasizing trauma and adversity and overlooking critical

cultural meanings and idioms of trauma, distress, and recovery (53). However, cultural literacy is essential in crises and context matters (54). Eurocentric approaches to care are often adopted without question, which can further marginalize refugee youth, potentially leading to their disconnection from formalized treatment and intervention services (55, 56). Researchers have suggested (57) that: "Contextual factors, including cultural, political and socioeconomic environments, influence explanatory frameworks for mental health problems in children, which in turn influence how distress and impairment are experienced and how symptoms are interpreted in a given society." Any intervention or prevention strategy developed for youth in the Bidibidi settlement must be grounded in their unique cultural and social contexts and include efforts to interpret the meaning of young people's expressions of distress and coping. Understanding young people's explanatory models of "(un)wellness" can help to tailor intervention practices better to galvanize their individual and collective resilience, strengths, and capacities. In addition, drawing upon and fostering South Sudanese cultural activities, celebrations, and networks within the camps, whether formal or informal, could help develop intervention practices and maintain cultural identity and rootedness.

There is a lack of documentation on the importance of service providers, such as social workers, and their role in ensuring refugees in Uganda have access to essential services. However, their work is vital. Many service providers are a part of the Refugee Eligibility Committee (REC). In contrast, others work with Non-Governmental Organizations (NGOs) to help with measures such as first aid, food distribution and health promotion initiatives. Local service providers must be prepared and committed to addressing the vulnerabilities of refugees and their families and national and international policies for social services provision. Moreover, it is essential to strengthen the resilience capacities of refugees to develop and nurture existing informal care systems that assist in meeting their health needs. Our study found that poor economic prospects and survival were the primary reasons why youth used and sold alcohol in the settlement. Therefore, policymakers should focus on long-term economic empowerment and youth employment to address this issue. Additionally, education on the short-term and long-term implications of alcohol use and abuse, including awareness raising and community sensitization regarding alcohol consumption, is crucial. It is also important to correct misinformation that alcohol can cure illnesses such as COVID-19. Our findings on why youth use alcohol as a coping mechanism can help inform policymakers on decision-making, resource mobilization and allocation for alcohol use services and treatment among refugee populations.

Moreover, in addition to good interpersonal skills to work with individuals and groups of refugees, there is an underlying expectation that service providers should exercise leadership in the planning and delivery of services. For example, identifying the health needs of refugees, mainly related to alcohol use and misuse, communicating with potential service providers, providing accurate information to refugees, acting as liaison officers in the community, and working as health care advocates can facilitate promptly delivering required health needs. Direct engagement with refugees allows service providers to understand refugees' lived experiences better and are better positioned to research issues, including health, culture, and other social determinants of health and wellbeing. In line with this, service providers must reflect on a culturally attuned framework to the health needs of refugees. Attaining these policy and practice goals continues to be a challenge as health services in Uganda face several

difficulties, including underfunding and understaffing. The support for humanitarian assistance and protection programs for refugees also face similar hurdles. Underfunded health programs inhibit not only the design and delivery of health services to refugees but also exacerbate their vulnerability to the risk of consequences. Accordingly, shame and stigmatization from self, family, and friends, as well as the host community, were reported as barriers to care, preventing affected youth from attending alcohol treatment services. Notably, youth can receive positive messaging and personalized interventions from service providers. Still, if they return to or live in a context where stigma prevails, all this work can be stunted.

Developing effective intervention and prevention strategies requires us to be involved and learn from the knowledge and experiences of young people who have been affected by violence, loss, and economic marginalization, especially refugee youth in camps. Their unique perspectives and experiences can help us better understand how alcohol use can become a pathway to addiction for them. Future research, policies and practices must be informed by young people's insights and proposed strategies to address alcohol use and its long-term implications. However, we must also understand that the lives of young people are not independent of their surrounding families and communities that encircle them (4). Thus, any future intervention policy and practice should also consider the perspectives of their families and communities. Moving away from an individualistic approach, we must engage families and communities as active protective mechanisms that can reduce the devastating impacts of war, conflict, displacement, and resettlement through support and protection for the youth.

## Conclusion

To our knowledge, this is the first in-depth study to explore alcohol abuse among war-affected South Sudanese refugee youth in Uganda. This article reveals a wide range of historical, political, cultural, familial, individual, community, and geographical factors that are perceived to influence alcohol use and abuse among war-affected South Sudanese youth living in the Bidibidi refugee settlement in northern Uganda. These factors are essential in stimulating further discussions to counter, buffer, and address the harmful use of alcohol among refugees. The findings show that alcohol abuse among South Sudanese refugees is precipitated by war and conflict experiences before, during flight, and after resettlement. Experiences of trauma, violence, separation from family, breakdown of cultural identity, poor prospects, economic marginality, and easily accessible and inexpensive alcoholic beverages within the Bidibidi refugee settlement are perceived main risk factors for alcohol use and abuse among the young population.

The data further reveal that many youths appear to be caught in a cycle of increasing alcohol consumption, which is influenced by the trauma of war, forced displacement, and the conditions of their refuge. Moreover, the youth highlighted the stigma and shame associated with their alcohol addiction, alongside the fear of seeking support at community health clinics. To tackle youth substance abuse in refugee camps, it is therefore vital to not only address past traumas that appear to drive young people to alcohol use but also the fear and shame that prevents them from seeking help. Addressing alcohol use and abuse among forcefully displaced populations requires a concerted effort from multiple sectors while involving several layers of engagement. This article contributes to an emerging understanding of how South

Sudanese refugees perceive alcohol use and abuse in their war displacement experiences, which can provide helpful insights for tailoring interventions to the needs of refugees with alcohol use and abuse problems. Applying group work skills and community work approaches, service providers can liaise between refugees, the government, policymakers, and local authorities to identify priority needs and the necessary resources to meet refugee health needs. These findings may contribute to improved resources and support for alcohol abuse treatment services in post-conflict and humanitarian settings in Uganda and beyond, particularly for young people in similar situations.

In line with the Global Strategy for the Health of Children and Adolescents 2020–2030, improving education, water, harmful alcohol use, and hygiene are critical to accomplishing SDGs, particularly SDG 3, Health and Wellbeing for All. To achieve this, greater attention to youth voices and perspectives, involving family and surrounding community, reliance on local cultural understandings of alcohol use and abuse, as well as health and wellness, is needed. Moreover, there is a need for an integrated multi-disciplinary approach to a practice involving social workers and other professionals such as psychiatrists, counsellors, and health workers to promote holistic responses. Given the consequences of harmful alcohol use on an individual's worth and dignity and the more significant implications for family, community, and society, it is crucial to improve refugees' access to substance use services. To comprehensively meet the needs of war-affected refugee youth, more substantial commitments are required for policymakers to work together with service providers because the knowledge, skills, and experiences of service providers are essential to effectively respond and address alcohol issues among refugee populations in precarious conditions. In the broader societal view, the socioeconomic and public health implications of harmful alcohol use among these war-affected refugee youth must be understood to inform relevant interventions at both individual and population levels, culturally and structurally competent policy solutions and appropriate livelihoods in resource constraint displacement environment.

## Data availability statement

The datasets presented in this article are not readily available because of ethical and confidentiality reasons. Requests to access the datasets should be directed to GM, godfrey.makoha@mail.mcgill.ca.

## Ethics statement

This study involved human participants. The McGill University Research Ethics Board 3 REB File#21-05-043 approved the study. The study was also conducted under the Office of the Prime Minister's local legislation and institutional requirements. The studies involving humans were approved by the McGill University Research Ethics Board 3 REB File#: 21-05-043. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

GM: project conceptualization, methodology, funding acquisition, data collection, analysis, writing, and editing. MD: paper co-conceptualization, writing, and editing. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Forgone healthcare for medically vulnerable groups during the pandemic era: experiences of family caregivers of young adults with substance use disorders in Zambia

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**Introduction:** Scholars worldwide have defined the COVID-19 pandemic as a mass-disabling event of our time. The situation is grave for families experiencing financial hurdles while caring for young adults in recovery from addiction problems.

**Methods:** Using semi-structured interviews with 30 purposively selected family caregivers (FCGs) of young adults with substance use disorders (SUDs) in Lusaka, Zambia, this study reveals several factors influencing forgone healthcare for this medically vulnerable group.

**Results:** Financial challenges and huge out-of-pocket bills; caregivers' perceived far-fetched recovery of the young adult; the cost of medication and transportation; the young adult's little perceived need for healthcare service use, their runaway and treatment elusive tendencies; caregiver concerns about contracting the virus, and the stigma associated with it; and a fragmented child and adolescent mental health system influenced forgone healthcare. The young adults were often unavailable for days and months, posing challenges to the continuity of care. Despite caregivers' acknowledgment of the availability of healthcare professionals, young adults with problematic substance use had limited access to SUD recovery services, resulting in adverse health outcomes. Results also show that most family caregivers encountered challenges in accessing and purchasing psychotropic medications, which were difficult to find during the lockdowns. Some family caregivers lost their sources of income by being laid off from work due to the pandemic and skipping work to attend to caregiving responsibilities. Most of those in self-employment had to close their business and stay home to look after their youth. Several caregivers kept their youth at home because they failed to access private residential SUD recovery services. Family caregivers mostly relied on outpatient public health services, alternative medicine from traditional healers, and faith-based healing, all of which some young adults rarely accessed because of their problematic behaviors of escaping healthcare.

**Conclusion:** These identifiable risk factors, and their detrimental consequences highlight the need for interventions to improve healthcare access for this vulnerable population. Supporting FCGs of addicted young adults is crucial in ensuring the well-being of both the caregivers and care recipients. Further research is warranted to explore potential solutions, such as peer support

programs, policy changes, and education initiatives for carers and recipients in the (post) pandemic era.

## Introduction

Family caregivers' lived experiences in caring for young adults with substance use disorders remain a critical yet often overlooked aspect of addiction recovery. These caregivers face many challenges while supporting their loved ones, navigating the complexities of addiction, and striving to maintain their wellbeing (1, 2).

Although research on forgone healthcare is widespread in developed countries and mainly focuses on individuals with health problems, there is a pervasive void in research on forgone healthcare in Low- and Middle-Income Countries. According to the extant literature, "The concept of foregone care focuses on conditions under which people chose not to, or are not able to, use health services despite perceiving a need for those services" [(3), p. 775]. In showing the paucity of studies on forgone healthcare in LMICs during the COVID-19 pandemic, Kakietek et al. (3) argued that "despite the greater vulnerability of households and fragility of the health systems, there are no published studies on the prevalence of foregone healthcare during the pandemic in LMICs" [(3), p. 772]. To fill this profound gap in research, this paper reports on the lived experiences of forgone healthcare among family carers of adolescents and young adults grappling with addiction during the COVID-19 pandemic in Zambia and argues that caregiving for young adults with substance use disorders is a challenging task, involving psychosocial, physical, and financial strains. This is because young adults with SUDs are among the medically vulnerable groups in society. Weitzman et al. (4) define medically vulnerable groups as those with chronic illnesses, for example chronically ill youth [(4), p. 450] who have an increased risk of developing severe illness if they contract a particular disease or condition. Due to the chronicity of their illnesses, these individuals are more susceptible to complications and adverse outcomes. SUDs are chronic illnesses which have been defined as "complex disorders that affect brain function and behavior, are characterized by impaired functioning and considerable harm to the individuals with the disorders and to society as a whole" [(5), p. 2]. Addiction scholars posit that as a medical brain condition, SUD involves the consumption of illicit substances like cocaine, cannabis, heroine or methamphetamine and legal substances like alcohol and prescription medications. Among legal drugs linked to substance use disorders, alcohol is the most prevalent (6), with affected individuals struggling to regulate their consumption (7).

According to Menon et al. (8), youth substance use problems are prevalent in Lusaka, Zambia, with around 38.5% of facility-based admissions related to alcohol use disorders whereas, 12.4% are attributable to cannabis or marijuana, cocaine, and heroin (9). Crane et al. (10) recorded a significant increase of 293% in hazardous alcohol consumption admissions between 2010 and 2014 at the country's largest psychiatric hospital. In more recent research on the prevalence of addictive behaviors among adolescents from 73 low-and middle-income countries, de la Torre-Luque et al. (11) found that Zambian adolescents had the highest regular and problematic use of alcohol. The social acceptance and prevalence of alcohol consumption as part of Zambian traditions and celebrations, coupled with the availability of cheap and unsafe varieties of alcoholic beverages due to economic liberalization, have contributed to the high rate of alcohol consumption in the country (8, 12, 13).

Moreover, the lack of recreational facilities for young people and elevated levels of poverty and unemployment are contributing factors to the increased intake of alcohol in Zambia, as stated by the Ministry of Health (13). All these factors indicate the widespread prevalence of SUDs in Zambia, emphasizing the need for further research on the experiences of caretakers who care for young persons diagnosed with SUDs, as research on caregivers of substance-dependent individuals is nearly non-existent in Zambia. Therefore, this study fills this gap in research on addiction care in Zambia.

In addition to creating changes in addiction problems, the COVID-19 pandemic has changed how individuals access and receive medical care. The pandemic's effects go beyond the direct impact of the virus, and it has also affected the healthcare-seeking behavior of individuals. Many individuals have been unable or unwilling to access healthcare services during the pandemic, leading to forgone healthcare. This phenomenon is a significant public health concern as it can worsen chronic conditions, delay diagnoses, and increase morbidity and mortality (14).

Several factors have contributed to the decrease in healthcare-seeking behavior during the pandemic, including the fear of contracting the virus, lockdowns, and stay-at-home orders. Financial constraints were also a significant barrier to healthcare, with many people experiencing job losses and reduced income. According to Kakietek and colleagues (3), close to 52% of respondents in Sub-Saharan Africa reported forgoing healthcare due to financial constraints as opposed to 16.7% who forwent care due to COVID-related reasons. Conversely, Menon et al. (14) found that most who had forgone healthcare had done so because they were concerned about contracting COVID-19 or burdening the healthcare system.

The consequences of forgone healthcare before, during, and after the pandemic are grave and long-term. Forgone healthcare can severely affect individuals' health outcomes, particularly those with chronic conditions. Delayed diagnoses can lead to the progression of diseases, and lack of medical attention can lead to increased morbidity and potentially life-threatening outcomes, and lower quality of life (15, 16).

The Canadian Centre on Substance Use and Addiction (17) reports that on a global level, alcohol use has dropped by approximately 10%–15% during the pandemic. However, various sectors of society, like the unemployed, those with alcohol abuse issues, and people in

precarious situations, have seen a rise in such consumption. For most young adults, the COVID-19 pandemic predicted increased substance use due to a sharp rise in depression, anxiety, stress, and boredom that came with the isolation (18). This resulted from disruptions in the daily routines of adolescents and young adults. School closures meant a breakdown in physical interaction with their peers and non-engagement in extracurricular activities that involve the participation of more than one person, such as sports.

While numerous studies have been done on the impact of the pandemic on young people's developmental outcomes, there is a paucity of studies on young people with problematic substance abuse, particularly regarding the lived experiences of family caregivers of adolescents and young adults with problematic substance use in Sub-Saharan Africa. This has limited our understanding of forgone healthcare for this at-risk group. The present research, therefore, aims to fill this knowledge gap.

## Brief overview of the situation of COVID-19 in Zambia

On 18th March 2020, Zambia recorded its first case of COVID-19 in a couple that returned from a holiday in France. Although the cumulative number of deaths has generally been low compared to other countries, the impact of the pandemic on families of young adults with substance use disorders has been grave. As of 28 June 2023, 347,928 positive cases were confirmed, with 4,064 deaths (19).

Even before COVID-19, Zambia's economic condition and outlook were bleak. Factors such as falling copper prices, a substantial external and internal debt burden, rising inflation, and poor management of the public sector (20) characterized the Zambian economy. Therefore, with the pandemic's adverse effects on the economy, the Zambian government lacked the necessary resources to tackle the additional economic challenges brought on by the COVID-19 pandemic, placing an undue burden on Zambian households (21). Furthermore, Saasa and James (21) note that economically afflicted homes are at a higher risk of experiencing even more severe economic circumstances due to the pandemic because, even before COVID-19 struck, Zambian households faced various difficulties such as poverty, hunger, and joblessness. Regrettably, these problems are predicted to worsen during this outbreak and beyond, as most individuals in the informal sector depend on daily income. In Zambia, approximately 87.5% are engaged in informal sector employment (22).

Despite not implementing a total lockdown, the Zambian government took measures to curb the virus, including travel restrictions, limitations on meetings in public spaces, stay-at-home orders, and social distancing. Like many countries in the region that implemented such measures, these measures had dire consequences on Zambian businesses and families, resulting in many individuals losing their jobs and income and consequently being unable to sustain their livelihoods and fend for people in their care (21). This situation made FCGs more vulnerable to the economic downturn as most were in sectors hard-hit by the pandemic.

As Finn and Zadel (23) show in their phone survey on monitoring COVID-19 impacts on households in Zambia, individuals engaged in non-farm businesses experienced a 71% reduction in income and an 11% complete loss of income, as shown in Table 1.

The massive loss of jobs in different economic sectors fueled this income reduction. For instance, the personal services sector was the second highest sector, with a 39% job loss after the tourism sector, which recorded a 71% loss of jobs among respondents in the survey by Finn and Zadel (23).

Figure 1 shows that job losses during the COVID-19 pandemic in Zambia were much higher in non-agricultural sectors, affecting many households in Lusaka that rely on personal services such as street vending, small enterprises, and domestic work.

Also, Paul and colleagues assert that "With a Gini index of 57.1, Zambia is also among the most unequal countries in the world" [(24), p. 2], with persistently high poverty levels that have stagnated at 54% for more than 10 years. Therefore, if left unabated, the pervasive inequalities entrenched in Zambian society will likely persist after this mass-disabling pandemic has receded. These underlying disparities, which affect access to resources, opportunities, and essential services, have profound implications for the wellbeing of vulnerable groups and the broader socioeconomic landscape of the country. Efforts to address these structural inequalities must be sustained and amplified to build a more equitable and resilient Zambia for its most vulnerable citizens.

In addition, school closures resulting from COVID preventive measures meant that many children were out of school and thus had minimal supervision from school. About 4 million learners in Zambia were affected by school closures brought on 20th March 2020 for an indefinite period (23). This move resulted in the drop out of school among children from at-risk households who could not engage in online learning. According to Finn and Zadel's survey, 89% of children attended school before the pandemic, but less than 44% were involved in online learning during the pandemic. Generally, Zambia has experienced high school dropout rates even before the COVID-19 pandemic began. For instance, the Examinations Council of Zambia recorded dropout rates of 44% among students in 2012 (25). Also, prolonged school closures when the pandemic was at its peak resulted in increased numbers of young women falling pregnant, whereas

TABLE 1 Change in income from four main household income sources since outbreak.

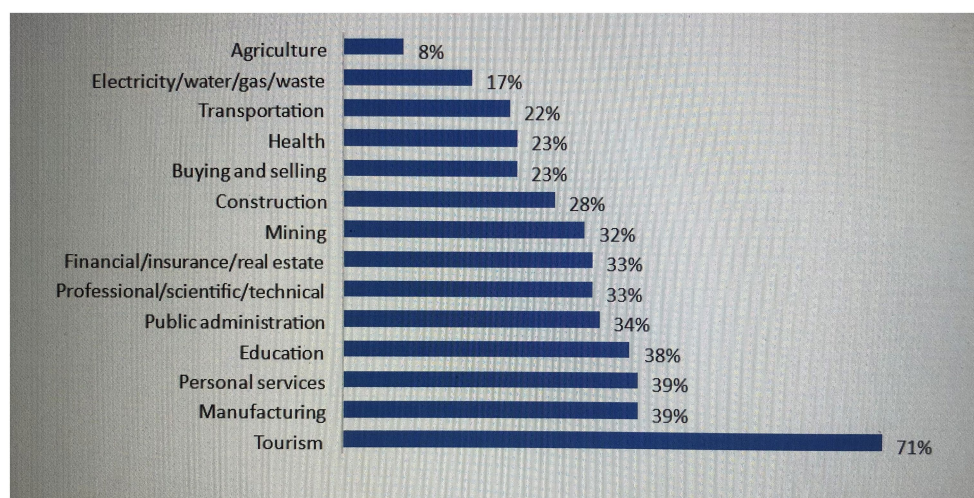| Household income source | Increased | Stayed the same | Reduced | Stopped |
|---|---|---|---|---|
| Farming, livestock or fishing | 18% | 23% | 51% | 8% |
| Non-farm business | 7% | 10% | 71% | 11% |
| Wage employment | 2% | 65% | 26% | 7% |
| Remittance from family in Zambia | 8% | 20% | 58% | 14% |

Source: Finn and Zadel (23).

**FIGURE 1**
Respondent job losses by sector since outbreak began. Source: Finn and Zadel (23).

young men resorted to illicit substance use and theft [(26), p. 2]. This was partly due to increased responsibilities for supervision, primarily by women, which affected their allocation of time to multiple commitments, thereby reducing oversight for young adults.

## An overview of mental health and addiction care services in Zambia

Mental health services in Zambia have a lengthy and intricate history. In the early 20th century, mental healthcare was basic and limited to several missionary hospitals (27). Following the end of British rule, the post-independence government acknowledged the necessity of establishing psychiatric services. Consequently, Chainama Hills Hospital was inaugurated in 1966 as the country's first public psychiatric hospital (28). During the 1990s, the country underwent a health system restructuring that disregarded mental health (29). Although there were growing demands to integrate mental health into primary care for improved accessibility, numerous obstacles impeded progress (29, 30). Several pilot programs exhibited success but lacked the required financial support and policy endorsement for further expansion. To date, mental health services in Zambia continue to confront numerous challenges Additionally, persisting stigma, inadequate mental health indicators, and limited data pose substantial barriers to service delivery, particularly within primary healthcare facilities where integration has occurred (30, 31).

In Zambia, mental health services are predominantly hospital-based and highly centralized (32). Moreover, psychotropic medications are usually costly and in limited supply at mental health facilities (10, 33) resulting in families bearing enormous out-of-pocket costs for healthcare (34). Thus, it is unsurprising that 2% of the national health budget is designated for mental health care (35). The small number of qualified psychiatrists and other mental health professionals (36), combined with an absence of public community-based substance use rehabilitation services, further complicates matters for family caregivers of young people with SUDs in Zambia.

Regarding addiction care, addressing SUDs faces multiple challenges due to a lack of resources and infrastructure (37, 38). The availability of detox and rehabilitation programs is scarce, leaving numerous individuals struggling with untreated disorders. Where services are available, treatment regimens include the prescription and administration of psychotropic drugs such as Diazepam (oral and injectable), Thiamine, Vitamin B Complex, Fluoxetine, and Niacin for those with alcohol use disorders, and Risperidone for youth with cannabis use problems presenting with psychotic features. Psychotropic medications for a standard prescription range from above K100 to more than K250. Services like counseling and psychotherapy, psychological assessments, screening for mental health conditions, linkage to other hospital services, health promotion activities in schools, and general community and youth friendly services are provided (39). In addition, faith-based and traditional healing services are also prevalent in Zambia's mental healthcare system and are used by SUD caregivers.

However, scarce rehabilitation resources in developing countries like Zambia increase the family caregiving role (40), with the weight of SUD caregiving primarily resting on women, typically the wives, mothers, and daughters of those affected by SUDs (41). These caregivers often do not possess the necessary knowledge about SUDs or the skills to provide optimal support, leading to negative outcomes for both patients and caregivers. This situation indicates a necessity for extended therapeutic intervention and community-based support to aid the recovery process of individuals struggling with substance abuse, enabling them to maintain their recovery and alleviate the hardships faced by their caregivers.

## Materials and methods

The data presented in this paper are part of a phenomenological (Doctoral) study on the lived experiences of family caregivers of youth with substance use disorders in Zambia conducted in the pandemic context between May and August 2022 (see Supplementary File). Recruitment of study participants was done with the aid of the clinical officers at Kanyama General Hospital (KGH) Mental Health Unit, who acted as gatekeepers and provided contact details of family caregivers of young adults who attended outpatient substance use recovery

services. The caregivers were contacted via phone, and details of the study were explained to them. When FCGs who were contacted refused to participate in the study, the clinical officers provided more contacts.

Participants in the study consisted of caregivers (aged 18 and above) for young adults with SUDs, such as alcohol or cannabis, ranging from 16 to 24 years old. This is because alcohol and cannabis misuse are prevalent issues among young adults in Zambia (9–13). In addition, at the global level, the World Drug Report (22) indicates that data from Western countries shows that "cannabis is a common drug of choice for young people" [(42), p. 6] citing easy availability and perceived low risk of harm as among the causes for increased use. Moreover, the latest report by the United Nations Office on Drugs and Crime (43) also shows increased cannabis use among young adults. Some scholars argue that the legalization of cannabis use for recreational purposes in most countries has led to an increase in use among most youngsters (44).

The purpose of the research was explained to potential research participants through direct phone conversations. This included discussing ethical concerns such as obtaining informed consent, ensuring confidentiality, and maintaining anonymity. Furthermore, the participants were informed about their right to take part in the study and were given the option to withdraw at any point, including during the interviews. Therefore, participation was voluntary, and the study involved a purposive sample of 30 family caregivers who gave written informed consent to participate in the research and for the interviewer to audiotape the interviews. Both male and female caregivers were invited to participate in face-to-face semi-structured interviews.

A detailed interview guide was developed by drawing insights from the key conceptual constructs of the theories guiding the main study (positioning theory and theory of caregiving dynamics) and as inspired by existing literature on the topic.

Before initiating the study, a preliminary test of the interview guide was done with individuals who shared similar traits (caregivers for young adults aged 16–24) with the intended interviewees but were not part of the study (45). This pre-testing aided in determining the clarity and comprehension of the questions and the effectiveness of the topic guides in producing data relevant to addressing the research questions (46). In general, the pilot study demonstrated that the interview guides were comprehensive and could obtain responses that would contribute toward addressing the research questions. No changes were made to the interview guide.

Two interviews were conducted, an initial interview and a follow-up interview after 4 weeks, based on the premise that collecting data over an extended period is suitable for unraveling caregivers' experiences during the recovery trajectories of youth with SUDs, which are chronic and relapsing conditions (47). Doing this helped to capture the changes in caregivers' experiences over time. That is, from the time their young adults were diagnosed with SUDs, to the time of the interviews. The interviews involved exploring the retrospective and current caregiving accounts of FCGs. This is because informal caregiving and recovery involve temporal phases or timelines of significant events (48, 49). All the interviews were conducted in safe spaces within Kanyama General Hospital and lasted up to 60 min.

Data was collected using an audio tape recorder by the author and transcribed verbatim with the help of two transcribers. Interviews were conducted by the author in the language that participants were

fluent in (English, Nyanja, Bemba) with no need for an interpreter because the author is fluent in all the three languages. Data analysis was done inductively using the Interpretative Phenomenological Approach (IPA) proposed by Smith et al. (50). The IPA is particularly suited for examining topics that have not been extensively researched or those that involve complex or ambiguous phenomena, as well as for understanding the real-life experiences of family caregivers in their unique sociocultural context, in their own words (51, 52). With the IPA approach, interview transcripts were analyzed systematically and qualitatively on a case-by-case basis, and a narrative account was created that exhaustively presented "the researcher's analytic interpretation" of the study's findings, with verbatim extracts from the participants' accounts [(50), p. 9].

Data protection of participants' information was ensured through unique identifiers of family caregivers such as FCG1, FCG2, etc. This helped in anonymizing the caregivers and protecting their identities (Table 2).

The study sample included different types of relationships between the caregivers and care recipients. Of the research participants, 17 were mothers [one mother joined her husband's (FCG23a) interview halfway], 7 fathers, 2 uncles, 1 brother, 1 sister, 1 husband, 1 wife, and 1 stepmother. These participants (males and females) were purposively selected to get a heterogenous sample of FCGs that that would provide multiple perspectives on caregiving for addicted youth. With regards the youth's diagnosis, 13 had cannabis use disorders, 8 had alcohol use disorders, 8 were diagnosed with a combination of alcohol and cannabis use, whereas 1 youth had alcohol and sniffing drugs. Overall, FCGs expressed concern about their youth having polysubstance use problems and were aware of the existence of a mixture of substances in addition to the prominent alcohol and cannabis use by the youth. The University of Zambia Humanities and Social Sciences Research Ethics Committee (HSSREC-2022-April-019) and Lingnan University provided ethical approval for the study. Institutional consent was also obtained from the Medical Superintendent at Kanyama General Hospital.

## Results

Caregivers recounted their lived experiences from the time the youth's problem began to the time of the interview. Findings from the first and second interviews indicate that even before the COVID-19 pandemic, FCGs experienced multiple challenges, including work disruptions, financial challenges, their children's problematic substance use and consequent dropping out of school (Table 3).

## Experience of addiction care before the pandemic

### Work disruptions

It is worth noting that even before the outbreak of the COVID-19 pandemic, some family caregivers were laid off from work due to missing work as they attended to caregiving responsibilities for their problematic youth. Caregivers often reported work disruptions when called upon to quickly attend to the youth in instances when they became violent and exhibited disruptive behaviors or when they relapsed and needed urgent medical attention, as seen in the accounts below:

TABLE 2 Sociodemographic characteristics of FCGs and their relationship to the young adult.

| Name | Gender | Age | Marital status | Employment status | Relationship to the young adult |
|---|---|---|---|---|---|
| FCG1 | Male | 42 | Married | Self-employed | Father |
| FCG2 | Male | 43 | Married | Part-time employment | Father |
| FCG3 | Female | 41 | Married | Marketeer/street vendor | Mother |
| FCG4 | Female | 43 | Married | Businesswoman | Mother |
| FCG5 | Female | 38 | Single | Self-employed | Mother |
| FCG6 | Female | 40 | Single | Employed | Mother |
| FCG7 | Male | 51 | Married | Employed (Farmworker) | Father |
| FCG8 | Male | 42 | Married | Employed | Uncle |
| FCG9 | Female | 49 | Widow | Employed (Maid) | Mother |
| FCG10 | Female | 54 | Divorced | Unemployed | Mother |
| FCG11 | Female | 52 | Widow | Hospital volunteer | Mother |
| FCG12 | Female | 53 | Married | Businesswoman | Mother |
| FCG13 | Female | 46 | Divorced | Trader | Mother |
| FCG14 | Male | 58 | Divorced | Artisanal artist | Father |
| FCG15 | Female | 47 | Separated | Teacher | Mother |
| FCG16 | Male | 48 | Widower | Security guard | Father |
| FCG17 | Female | 40 | Married | Hairdresser | Mother |
| FCG18 | Female | 41 | Widow | Restaurant owner | Mother |
| FCG19 | Male | 49 | Married | Security guard | Uncle |
| FCG20 | Male | 32 | Married | Businessman | Brother |
| FCG21 | Female | 43 | Married | Businesswoman (salon) | Mother |
| FCG22 | Female | 64 | Widow | Self-employed | Mother |
| FCG23 | Male | 63 | Married | Tailor | Father |
| FCG24 | Female | 42 | Married | Unemployed | Mother |
| FCG25 | Female | 23 | Married | Unemployed | Wife |
| FCG26 | Female | 60 | Widow | Trader | Mother |
| FCG27 | Female | 28 | Married | Trader | Sister |
| FCG28 | Female | 43 | Married | Unemployed | Stepmother |
| FCG29 | Male | 37 | Married | Self-employed Mechanic | Husband |
| FCG30 | Male | 58 | Married | Civil servant (Office orderly) | Father |

I could not go to work for fear of him creating problems around people… I was laid off at work because I was not going every day, employers are different, some are nice, and some are not nice and cannot understand my situation (FCG7, Father).

Even if I am scheduled to go to work, I fail to do so. I stay home so that I can observe him. When his temper goes down, the violence finishes, and he goes back to normal; maybe that's when I can go to work the following day (FCG30, Father).

I am usually disturbed to find money for food, and my eyes are just on him. If I am at the market selling, I would be called often to go and see what he is doing. So, most things have been disturbed (FCG12, Mother).

The above narratives show how the youth's problematic behaviors affected family caregivers. In times of the youth's relapse, caregivers abandoned and missed work to monitor the young adult, and some experienced grave consequences of being laid off from work because of their erratic attendance to work responsibilities, which was affected by the need to care for their youth. For youth with runaway tendencies, their caregivers also had to forgo their small personal businesses to search for them. Some opted to stay home for fear that their child would run away.

I cannot work properly or look for money as I should…I try, I hustle, you'll find that you plan that now let me do some work, but now being a parent and one who monitors the child, you find that one week, two weeks, she's nowhere to be found. So, you abandon your work and get in the job of searching for her (FCG3, Mother).

TABLE 3 Themes on the experience of addiction care before COVID-19 and during the pandemic.

| Superordinate theme: the experience of addiction care | |
| --- | --- |
| Theme | Sub-themes |
| Work disruptions | Missing work |
| | Attending to caregiving responsibilities |
| | Youth's problematic and disruptive behaviors |
| | Young adult's relapse |
| Young adult's dropping out or school | Young adult's preoccupation with substance abuse |
| Loss of income and financial difficulties | Stay-at-home orders during COVID.19 pandemic Loss of employment |
| Difficulties keeping the young adult indoors | Young adult's unabated roaming and runaway tendencies Young adult's cognitive impairments |
| Accessing healthcare | Adherence to COVID regulations |
| | Challenges in accessing medication |
| Forgone healthcare | Young adult's treatment elusive tendencies Lack of family support |
| | Caregivers' perceptions to a far-fetched recovery |
| | Manipulation and extortion of healthcare fees The young adult's outlook on COVID |
| Coping mechanisms | Religious coping |
| | Problem-focused coping |
| | Emotion-focused coping |

> He really troubled me such that I stopped leaving the house in the fear that he would run away from home…When you leave the house, you'll hear that he ran away, and people bring him home saying we picked him from a certain place… I even stopped going to church (FCG26, Mother & Widow).

The challenges highlighted in the excerpts above show how caregivers experienced difficulties in their caregiving even before the pandemic. This was worsened during the pandemic because of the socioeconomic changes that came with it, as discussed earlier. For instance, failure to properly engage in work activities due to the constant search for a runaway youth with SUDs or the need to stay home to monitor the youth's movements resulted in dwindled finances and opportunities to engage in other meaningful activities like attending church. The caregivers' compromised financial situation adversely affected their capacity to care for their young people.

## Dropping out of school

Even before the COVID-19 pandemic, most young people with substance use problems were reported to have dropped off from school, resulting from their addiction to alcohol and cannabis.

> He stopped going to school on his own. We used to tell him to go to school, but he stopped. He used to be chased from school because he dressed like a junkie (FCG19, Uncle).

> At first, he used to go to school to learn, but afterward, he stopped going to school and became something else (FCG30, Father).

> My son used to be very brainy, and if you ask about him at his school, they will tell you about him. He stopped going to school in grade 10 (FCG18, Mother & widow).

All these demonstrate the difficulties that young adults contending with SUDs face regarding educational attainment. This disappointed family carers who experienced an ambiguous loss of "an intelligent child who would have been." Similarly, existing research shows that students affected by SUDs faced lower academic achievement than their peers (53) because of their preoccupation with substance use (7). Family caregivers consequently had a huge burden of care in the home because their emerging adults with SUDs were not in school.

In Zambia, emerging adults transitioning from adolescence to adulthood who are affected by addiction have been highly labeled as "junkies." This term has been normalized by citizens including FCGs, a phenomenon that has led to the entrenched stigmatization of this population. Even before the pandemic, the perceived "wasted life" of these emerging adults by members of society emanated from the youth's persistent use of substances, compulsive use despite negative consequences, disruptions in daily life activities, and issues with interpersonal relationships. Despite the evident deleterious effects of SUDs on the youth's psychological, emotional, physical, and social functioning, some were reported as enjoying being hooked on substances. One stepmother explained, "I asked him what is that thing that restrains you from quitting smoking? He said aah I do not know it…I cannot stop these things coz they are good" (FCG28, Stepmother). Similarly, a father of a youth with alcohol use disorder indicated that "When he has not taken alcohol, he is normal, but himself says that I do not feel good when am normal. I see people wanting to kill me, they are chasing me, and things like that" (FCG23a); depicting the unpleasant hallucinations that some individuals with SUDs experience. For such emerging adults, perpetual intoxication with alcohol and/or cannabis is better than being sober or "normal," and the use of healthcare services comes into the picture when they are in a physical health crisis. Some caregivers indicated that their substance-dependent youth were part of a subculture of "young adult junkies" influenced by peer pressure and difficult to manage.

> These children are in groups, he would like to stop but due to those groups, he still goes back… he started hanging around with the friends who smoke, and drink and he started doing those things again (FCG9, Mother & Widow).

## Impact of COVID-19 on addiction care for young adults

When the pandemic began, FCGs' initial challenges with addiction care for their emerging adults became even more complex. This was mainly due to the loss of income and its related financial difficulties.

### Loss of income and financial difficulties

Findings show that most FCGs worked in the informal sector as farm laborers, house helpers, salon attendants, and in personal businesses such as tailoring, mechanics, and street vending. Therefore,

the stay-at-home orders for non-essential services meant losing their incomes and businesses. As such, the pandemic exacerbated the predicaments of families already susceptible to adverse economic conditions. This situation made caregiving challenging for most FCGs who experienced financial hurdles due to loss of livelihoods.

As Muzyamba (54) notes, during the pandemic, a sharp increase in unemployment and poverty levels was observed as individuals were unexpectedly cut-off from their daily sources of income and livelihoods and had dwindled out-of-pocket expenses for their survival (54).

One single mother explained how even getting a coin became a challenge during the pandemic:

> During COVID-19, money was very hard to find, such that even a coin was hard to find… It was very hard to find K100 transport to take him to Chainama because I could not go alone. I needed to go with someone (FCG13, Mother).

A father who began caregiving for his son diagnosed with alcohol use disorder in 2010 indicated, "It was crucial, it was difficult… The issue of masks, sanitizers, and all… these things we usually do not have money to be buying, to make masks, buy sanitizer every time (FCG23a, Father).

The above quotes illustrate the financial difficulties experienced by carers of young adults in addiction recovery who were experiencing financial problems but needed someone to accompany them as they took their child to the country's largest psychiatric hospital, as in the case of FCG13. Because Chainama Hospital is located on the outskirts of Lusaka City, most caregivers reported challenges with transportation, and this was worsened during the pandemic due to disrupted cash flows for most caregivers who were in personal services and self-employment. For FCG23a, he disclosed having challenges purchasing things like face masks and sanitizers during the pandemic, which were non-essentials for him before the COVID-19 outbreak.

It is worth noting that in addition to the loss of income, most FCGs lost moral authority over their youth. Carers attributed this loss to the onset of their youth's SUDs and the consequent cognitive and behavioral changes which included increased impulsivity, disobedience, lack of self-inhibition, physical and verbal abuse. While one father noted that his son was not pleased with him, even though he was doing something good, an uncle explained his nephew's unheeding attitude toward good advice.

> He is not happy even if you try to do something good for him… he is not seeing that these people are doing good things for me… Sometimes after cautioning and encouraging him to change, he would get frustrated and keep a grudge. He would sometimes leave home and not come back again (FCG2, Father).

> We started noticing his behaviour changing because he was meeting different people and his drinking habits went up. After we saw that, we tried to sit him down and talk to him, but he did not listen (FCG8, Uncle).

The experiences of these caregivers depict their diminished opportunities to communicate with, and counsel their youth. It entails

a loss of caregiver control over the youth with limited moral and physical oversight.

Despite the loss of moral authority triggered by the youth's addiction, all caregivers acknowledged that their relationship with the youth before they developed SUDs was cordial and characterized by mutual respect. This was irregardless of the socio-economic status of the FCGs. Interestingly, even after their youth's diagnosis with SUDs, some caregivers reported that their care recipients openly expressed their love for them and acknowledged their efforts in helping them recover. In narrating the youth's appreciation of carers' support, FCGs gave the following accounts:

> Daddy I also think about you, it's just that you are not working, otherwise, you love me. Mummy, you take care of me, you love me (FCG23a).

> Our relationship is ok even though sometimes things do not go well. Sometimes he is drunk; he does this and that, but when he is normal everything is just ok. Like the day before yesterday, I was talking to him that my son, do you know that I trust you because I know you are the one who is going to take care of me and your sister. When I told him this, he just kept quiet and listened to what I was saying without answering me. We slept, and in the morning, he went for work, and went to drink. I thought he was at the carwash he went to get drunk and came home and told me that mum I heard what you said yesterday. I know, I love my family, I love you mummy… I know that I abandoned school, but it's not because of you, it's me and my inappropriate behavior. But everything I am doing mummy, I'll stop. He cried, and cried and cried, and I watched him until he finished, got up and went to sleep (FCG9, Mother & Widow).

However, despite these affirmative proclamations, the youth's addiction presented challenges in keeping them indoors during the peak of the pandemic as they desired freedom to go out and access the substances.

## Difficulties in keeping the young adult indoors

For the youths, the COVID pandemic did not make much difference to their situations that existed before the pandemic. They often roamed about unabated by stay-at-home measures and actively searched for cheap locally brewed alcohol and cannabis, which were readily available. Although the pandemic context required controlled movements, the young adult's non-adherence to this increased their caregiver's stress and anxiety.

For instance, several family caregivers reported challenges in keeping their youth indoors during the stay-at-home orders instituted by the government. The young adults continued their daily movements as they did before the pandemic, and it was difficult to constrain them. The following accounts reveal the challenges experienced by FCGs in ensuring that their young adults adhere to COVID-19 regulations:

> When COVID was a problem, I used to make efforts that he should minimize his movements, but it was not possible. I was scared that if COVID was there, maybe he would be among those with COVID, or he would bring COVID home and infect his friends in the house. But it wasn't easy because he was rarely

home. When it's morning, he will leave home. Early in the morning, he would go, and he would come maybe around 9 a.m. when he wanted to eat breakfast. When he eats, he goes, and he'll come back at perhaps 2 or 3 p.m.; he goes again and would come back at 9 or 10 p.m. just like that (FCG9, Mother & Widow).

The child is not the kind you can make to stay home. You tell her, "look there is this disease; please stay home you rest, look put on this mask," since the person is confused… You cannot tell her that look; there's COVID, so do not go, do not move around; put on a face mask. She cannot comprehend that (FCG22, Mother & widow).

It was difficult because I was limited, and he would not follow COVID-19 Instructions. I reached the extent of going to buy for him cigarettes so that he did not go outside, but he still wanted to go out because he thought that the home was a jail cell until other people said that I should be letting him go sometimes (FCG12, Mother).

The above accounts of mothers of young adults with addiction problems reveal the difficulties they encountered in their attempts to constrain their children from unnecessary movements during the stay-at-home orders, what I call "quarantine-averse behaviors" that were risky and deviated from the global COVID norms that individuals were required to abide by. These mothers also had challenges having their substance-dependent children adhere to COVID-19 regulations, such as wearing a face mask. For FCG22, she attributed her daughters' difficulties understanding the importance of abiding by the COVID-19 protective measures to a disordered mind. In the case of FCG12, her son's non-adherence to COVID-19 guidelines prompted her to resort to purchasing cigarettes on his behalf in the quest to keep him indoors, but this proved futile because her son felt like he was being imprisoned.

Although most FCGs encountered difficulties with keeping their substance-dependent youth indoors, stay-at-home orders made the surveillance of youth with runaway tendencies much easier. These orders accorded FCGs the moral and physical oversight on their youth during the pandemic, where being cooped up was a "normalized" phenomenon. While FCGs felt they were missing out on other meaningful activities due to staying home monitoring their youth, the young adults were reported as having a sense of lost freedom.

These perceived changes in daily routines of youth with SUDs under "lockdown" caused stress in the youth who desired to go out as they did in the pre-pandemic times. In line with the Lifestyle-exposure theory (55) and the routine activity theory, risky lifestyle behaviors such as substance abuse among frequent users affects their daily routines that are characterized by a preoccupation with acquiring and using harmful substances and engagement in deviant behaviors (56). Consequently, this poses challenges in caring for this population and results in postponed healthcare because young adults are often unavailable.

These findings concur with Hawkins (57), who asserts that substance use disorders result in low levels of inhibition and poor judgment among those affected, especially emerging adults. She further notes, "The youth often believes s/he is fine, perhaps no

different or even better off than peers, and may be highly resistant to any form of intervention" [(57), p. 203].

## Accessing healthcare: adherence to COVID regulations

Although the fear of contracting the virus was widespread among FCGs and other citizens in the country (21, 54), most family caregivers in the current study braved the virus and could access healthcare professionals based on given appointments. They reported that access to care at the mental health unit of Kanyama General Hospital was facilitated by adhering to the COVID-19 regulations of washing hands with soap, social distancing, hand sanitizing, wearing a face mask in public places, and covering the mouth with an elbow when coughing and sneezing.

When we used to come here during COVID-19, we used to wash our hands and sanitize, they would give us medicine, and they would do everything quickly so that we do not waste time there (FCG17, Mother).

When we reached the hospital, they would give us face masks and they would first test us for COVID-19 (FCG30, Father).

This shows the FCGs' willingness to respond to their young adults' addiction care needs during the pandemic. Strict adherence to these guidelines as a pre-requisite to accessing healthcare services shows how FCGs, despite being worried about contracting the virus, did not shun away from receiving help from the hospital because they aimed to facilitate the youth's recovery and return to normalcy.

Findings reveal that although most FCGs attended healthcare, there was a noticeable gap in treatment for young adults struggling with alcohol and cannabis use disorders that were exacerbated by the COVID-19 pandemic, where spaced appointments led to approximately 30% loss of clients who could not be retained in treatment (58). Most did not return for their scheduled appointments which were highly spaced for chronic conditions. The appointments were given for 3 months for non-acute conditions, resulting in the loss and non-retention of most young adults in addiction care.

## Challenges in accessing medication

Regarding medication purchases, FCGs also noted challenges accessing needed medicines during the pandemic.

We would buy medicine from anywhere as long as we find it. And medicines were hard to find because when you go to a certain place, you find it's not there, you go to another; it's not there. So, things were challenging when the corona came… Things are difficult, borders, where things come from, are closed… where medicines come from, they say this place is closed, and people are not traveling. Borders are closed. When you come to the hospital, quite alright you can find the doctors, and they prescribe for you, but for you to find the medicine is very difficult… for us to find the medicine we used to move in different places (FCG6, Single mother).

This mother's story demonstrates the difficulties that came with closed borders during the pandemic, particularly in accessing the

needed medications to treat addiction problems. This was worse for countries like Zambia, which do not manufacture most psychotropic drugs but rely on imports from pharmaceutical companies in countries like China, India, the US, and other countries with advanced medical technologies. Although healthcare personnel were available and would write prescriptions for the caregivers when medicines were unavailable at Kanyama General Hospital, caregivers still struggled to access the medication, and this negatively impacted the recovery of their youth, making them more vulnerable to the chronicity of SUDs during the pandemic. In their phone survey during the first wave of the pandemic, Finn and Zadel (23) recorded that 16% of respondents attempted to purchase medicine, but their efforts were futile. The increase in prices and limited supply of medicines on the local market made access to essential medicines a nightmare for families of individuals affected by addiction problems.

## Factors contributing to forgone healthcare

Several factors contributed to forgone healthcare. Most of these existed before but continued and worsened during the pandemic. Issues such as the young person's treatment-elusive and runaway tendencies, lack of financial support, perceptions of a far-fetched recovery, manipulation and extortion of healthcare fees were further exacerbated during the pandemic and resulted in forgone healthcare.

### The young adult's treatment-elusive tendencies

The likelihood of forgoing healthcare during the pandemic was higher for FCGs of treatment elusive youth and those with runaway tendencies. Youths who actively refuse treatment are a massive crisis in addiction care and a predictor of forgone healthcare. A study by Waldron et al. (59) mirrors the challenges parents face when they attempt to get their substance-abusing young adults to enter treatment for drug abuse. For instance, most family caregivers needed to visit the hospital with their youth. Still, they could not due to factors such as the treatment elusive tendencies of young adults with addiction problems.

In their quest for freedom from stay-at-home orders, most youth ran away from home and consequently missed out on healthcare, which their FCGs forwent because of the young adult's unavailability. Caregivers' narratives revealed that some youth left home to live with their substance-abusing friends, others wandered off in search of alcohol and/or drugs and made the streets their new home. One father who began caregiving for his son in 2020 remarked, "He would run away from the house sometimes and not sleep home… he was found with his friends then apart from that in 2021, he became worse. He even stopped school. He used to run away with his friends" (FCG2, Father). Similarly, a stepmother indicated, "Sometimes he would stay 2 days without coming home, after that he comes back home. When you ask him where he's been, he says he was in the streets… it's a challenge because he's still in the habit of running away from home. He does not stay in one place" (FCG28, Stepmother).

Consequently, caregivers who forwent healthcare experienced adverse health outcomes for their youth, whose recovery trajectory was prolonged by a lack/limited use of healthcare. This also increased the risk of poor mental and physical health for young adults. For instance, a widowed mother who had been caregiving since 2017 to a young adult with both alcohol and cannabis use disorders and serious runaway tendencies shared the following ordeal that happened in the pandemic context:

> I also went to social welfare and had him registered. I was told to take him there, but he ran away when I tried to take him. So, I went back home because I was only taking him there because they wanted to see him…I came back home and never went back to the social welfare offices (FCG18, Mother & Widow).

The above account shows the missed opportunities for addiction care for youth with runaway tendencies and the adverse consequences to their physical health. This scenario requires a strengthened community mental health system that can reach out to such a population and help reduce the treatment gap, more so in pandemic times. This is because young adults with SUDs are challenging to serve (57) and engaging and retaining them in treatment and other essential services is often problematic, resulting in poor outcomes.

Also, the spaced appointments given for people with chronic illnesses during the pandemic made most of this population fall out of care. The lack of family support also aggravated the situation of forgone healthcare experienced by carers of young people with SUDs.

### Lack of family support

For some caregivers, a lack of support from close family members made them forgo healthcare for their youth. For instance, when FCG21 visited the hospital and did not find the healthcare professionals who had gone to attend a funeral, her husband mocked and verbally abused her for wasting transport money that he gave her and their son for travel to the hospital. She explained that:

> We came here and found the grill door locked. We asked around, and we were told that the doctor had gone to a funeral… That's how we returned home, and the father said, "You did not find them, eh? You've destroyed my transport, I gave you money for transport, but it's been wasted" … we did not come back again, because we were shouted at by the one who gave us transport money (FCG21, Mother).

Later in her interview, this unsupported mother lamented that she shouldered the caregiving responsibilities unaided financially and emotionally despite having a husband. She explained that because of her husband's negative reaction and lack of support for their son's recovery, she did not return to the hospital until the day she was contacted for recruitment to participate in the study. Her ordeal reveals how the lack of support from significant others potentially results in forgone healthcare for young adults with substance use problems. This adversely impacts their recovery trajectories due to the lack of financial aid, impeding receiving much-needed services. As this occurred during the summit of the pandemic when access to income was a challenge for many vulnerable households, every penny counted, leading to frustrations when monies spent (in this case on transportation to the hospital) did not achieve the intended purpose. While FCG21's husband saw it as a waste of money and refrained from financially supporting their son's recovery, this move harmed their son's mental and behavioral health and aggravated the chronicity of his SUDs.

Furthermore, this primary caregiver's source of income was lost after her salon got broke. Providing holistic care to her son and his family without the support of her husband, she explained:

> My son's problem started in 2019 when he went to smoke cannabis. He has a wife and one small child at home. I am the one taking care of them. When he impregnated the lady, they brought her to us, and I am the one taking care of them…I reached a point where my salon got broke. Yes, I've stayed 3 months with a broke salon, because when I find money I give them for feeding, for their child, for going to the clinic, for the wife, and their house for rent (FCG21, Mother).

This mother's loss of an independent source of income during the pandemic increased her susceptibility to her husband's verbal abuse as she was adamant to continue providing care to a substance-abusing son, his wife, and child; a situation her husband did not approve of. She was emotionally and financially vulnerable and consequently forwent care for her son.

## Perceptions of a far-fetched recovery

Also, frustrations stemming from perceptions of a far-fetched recovery of the youth with chronic and relapsing SUDs, which continued unabated even during the pandemic, resulted in non-take-up of care as FCGs experienced a sense of futility in their efforts to facilitate the young person's recovery. Most caregivers were frustrated about their child's behavior, which posed challenges in accessing and utilizing the available services. As one father remarks, "I am always worried…We think of what we will do, which seems farfetched; we are in a dilemma. How are we going to deal with it? Where will we get help, so our child returns to normal? What will we do? We have gone to many places, desiring that he should stop drinking alcohol, but we are just writing on water. Nothing is happening" (FCG23a, Father). For this father, his use of the metaphor "we are just writing on water" signals the farfetched and seemingly unattainable recovery of his son. This situation led to feelings of helplessness and an "emotional overload" (60) on the part of this male family caregiver who had run out of options and was in a predicament on the next step to take.

Similarly, in expressing her frustration and the uphill battle she was experiencing concerning her daughters' non-recovery and the perceived lack of therapeutic gains, a widowed mother forwent healthcare after several failed attempts at facilitating the recovery of her cannabis-abusing daughter over time. For her, the daughter's non-response to medication was a misuse of drugs that would help another person. Her unmet treatment expectations resulted in her non-continuation of purchasing medicine for her daughter from the private clinic.

> I just saw that even though I was going to get her medication, I just realized that the medicine, which is supposed to help other people, I am getting, and things look like they are not changing, no let me stop. We used to come with her; when they were interviewing her in there, she would run away, and the doctors in there would chase after her and drag her back. They would jab her; maybe this injection will help but to no avail. The medicine has refused to work! Mmm, she's just like "umungu ulya ushipya" ['an African pumpkin that does not cook'] (FCG22, Mother & Widow).

This widowed mother's sentiments and use of a metaphor in describing her daughters' non-response to medication illustrate the intense frustration, disappointment, and psychosocial burdens that family caregivers experience when medical interventions for addiction problems prove ineffective. The unfortunate result is forgone healthcare for medically vulnerable youth with chronic SUDs. Even during the interview, she reported that her daughter was still in a condition of relapse. With dwindled finances during the pandemic, she could not afford to continue purchasing medicines from the private hospital for her daughter.

> Since it was a private hospital, I would get the medicine, and then I realized that Ah, I will not manage. The father is not around, I am alone, and I always have to be paying money (FCG22, Mother & Widow).

Coupled with frustrations about the seemingly unattainable recovery of her daughter, FCG22 also experienced the adverse effects of a fragmented child and adolescent mental health system, contributing to her decision to abandon care. This fragmentation of mental health services preceded the pandemic but was aggravated by it. In Zambia, there is a pervasive gap in the continuum of care for adolescents and young adults with addiction concerns and other mental health problems (31, 38).

## Manipulation and extortion of healthcare fees

Some caregivers who opted to seek addiction care services from faith-based and traditional healers forwent care when they were charged exorbitant prices and told to purchase things like anointing water, anointing oil, and other items that these healers prescribed for the treatment of the young adult, and yet saw no change as evidenced in the story below:

> "When the problem was just starting, we used to go to like churches, they would pray for her by a Papa, but he never told me what exactly was causing my daughter to be the way she is… I saw that I was not finding any help because when they prayed, they needed to tell me the cause of my child's problem, so I knew, but there was nothing like that… In the end, I gave up and told myself that I wasted time and the money I get is through struggling. When I go to a pastor, they tell me to bring such an amount of money for them to pray for my daughter's recovery. I release that money in my poverty, they pray for my daughter, and nothing is happening. So, I just said that I'll never go to traditional healers. If it's traditional healers, I never tried them. If a pastor wants money, what about a traditional healer? How much will I give them? So, I just abandoned everything" (FCG3, Mother).

Also, two widowed mothers narrated the following:

> I bought anointing water and anointing oil. I bought it. It was K100 that 750mls, and I was given a bottle that I should give him to drink and also to sprinkle where he sleeps. Things did not change; I stopped (FCG9, Mother & Widow).

> I went to the Traditional Doctor to access medicines, and we were told that he needed to be cleansed of ghosts, and he requested K1500, but I failed to find it (FCG26, Mother & Widow).

These mothers' accounts show how some FCGs who sought help from faith-based healers and traditional healers had to forgo healthcare because of logistical constraints like lack of finances and a perceived lack of positive outcomes for the young adult after accessing treatment. Also, we see how sociocultural factors such as beliefs on the causes of addiction (for example, ghosts) and other mental illnesses shape mental health care in Zambia (61). Although accessing healthcare services from traditional and faith-based healers is predominant in Zambia, some providers extorted their service fees during the pandemic, resulting in the abandonment of care among family caregivers.

## The young adult's outlook on COVID

It is worth highlighting that forgone healthcare was also due to a perceived lack of susceptibility to contracting the virus among young addicts. Such views made some adolescents and young adults not attend healthcare during the pandemic. Moreover, before accessing any services at the hospital, everyone needed to get tested for COVID-19. As Daabek and colleagues note, in addition to socioeconomic status, "personal conducts and/or beliefs, can lead individuals to forgo or postpone identified healthcare needs" [(62), p. 2,973]. This was particularly true for most young adults with addiction problems who believed that COVID was a scam, and they were not among those who would contract the virus:

> During the time of COVID-19, he never used to pay attention to it. He used to refuse that there's no such a disease, but for us, we used to adhere (FCG28, Stepmother).

> Even when you talk, he would say COVID is a scam. I am just ok. I cannot get sick, others will get sick (FCG9, Mother & widow).

Contrary to such beliefs held by these young adults, studies have shown that individuals with SUDs are at a higher risk of COVID-19 infection because SUDs are associated with various cardiovascular and pulmonary diseases (63, 64). This population's multiple comorbidities make them highly vulnerable to infections, which are risk factors for COVID-19 (65). This demonstrates that forgoing healthcare for this population during the pandemic has potentially deleterious effects on their health into adulthood.

In highlighting the difficulties encountered in having the youth adhere to COVID regulations, one uncle explained, "My nephew used to throw away the mask if he did not feel like having it on" (FCG19, Uncle). This demonstrates the increased risk of contracting the virus in this population of emerging adults who are not in their right frame of mind because of an impaired cognitive capacity emanating from chronic addiction.

Despite the various challenges and reasons for forgoing healthcare, most family caregivers adapted to their situation and used different coping strategies based on their caregiving context.

## Coping mechanisms employed by family caregivers

Prior studies have shown that caregivers frequently use coping strategies to navigate the terrain of providing care to those with addiction problems. Family caregivers have had to navigate a pandemic while also managing the addiction of their loved ones. During COVID-19, these caregivers faced additional stressors, such as social isolation, economic hardships, and inadequate access to support resources, as seen in the current study.

While seeking support from online communities, reducing stress through self-care activities such as meditation and exercise, and utilizing virtual therapy sessions were commonplace among FCGs in developed countries (66), FCGs in the current study coped with their challenges in diverse ways and employed psychological and emotion-focused coping, as well as problem-focused coping strategies, albeit in a unique way. Although several family caregivers used ingenious coping strategies that helped them adapt to their situation and the crisis, some strategies were maladaptive and had adverse long-term effects.

## Religious coping

Religious coping was common among FCGs, who all subscribed to Christianity, albeit with different religious denominations. They reported having an inner resilience based on their belief in God and that whenever things became very tough in their caregiving, they left everything to God through praying. This staunch religious belief can be seen in the expressions of FCGs below:

> I've seen that the burden is lighter; it's because every time of my life, I have put myself in God… Yes, I am really strong in prayers. Even for this child to be alive today and they have not killed her, maybe it's being strong in prayers (FCG22, Mother & Widow).

> Do you know that taking care of such a person is not easy because the landlord can even chase you out of the house and sometimes the neighbors laugh at me that I have a crazy child, so I just need to be strong, that is why I have said I also need to pray, even Jesus said that we need to be praying. So, we pass through different problems and leave them in God's hands (FCG7, Father).

## Emotion-focused coping

Concerning the experience of stigmatizing sentiments from some community members, caregivers found ways of managing the stigma attached to having a substance-dependent child. Using emotional coping, they often ignored stigmatizing comments and pretended not to have heard the negative sentiments. Some quickly entered their homes and started praying, crying to God, or reading the Bible, whereas a few directly confronted the perpetrators by giving them a piece of their mind through real-life examples, as FCG21 did when she said:

> Being lame comes even in adulthood. You can be born without any defect, but you may develop problems with your leg, so let us not laugh at each other, those of us who have borne children. I never knew my son would find himself on such a path (FCG21, Mother).

By retorting in this manner and confronting societal stigma, this mother positioned herself as her son's advocate and, at the same time, conveyed to the perpetrators of the stigma that every young adult is at

risk of addiction problems and that parents should desist from stigmatizing tendencies.

Conversely, a father reacted to stigmatizing sentiments by posing thought-provoking questions to perpetrators:

> Have you ever thought if it was your son or daughter who's in the same situation, how would you take it? Then they would say mm I think that's a very good idea, so we should not be laughing at such people, but we should just find ways, if there's a way of helping, let us help (FCG1, Father).

Regardless of their psychological and emotional challenges, family caregivers noted positive changes in their daily lives. By reframing their minds, they developed positive self-perceptions of growth and gained new insight into how to care for a substance-dependent young adult.

> "I see myself as a grown-up person… I just feel that I am a person who is responsible" (FCG6, Single mother).

> "Now I have experience in taking care of him. I do not have to speak to him rudely. When giving him food, I do not have to call him harshly. I now have experience, and I know him" (FCG26, Mother & Widow).

## Problem-focused coping

With regard to problem-solving coping mechanisms, some family caregivers engaged in a re-ordering of their priorities for caregiving. For instance, when medications were scarce and expensive due to border closures, the first thing that FCG6, a single mother, did was to make sure that she bought the son's medicine to last him a month before anything else. Although doing this was less financially stressful for her, it posed challenges in meeting the needs of her other children, like buying enough food for them.

> When I have money, I buy medicine for a month. Now if I do not have money? And we make sure that before we even think about food, we have to think about his medicine and how long it will last…if I get money and buy food, where will I get the money to buy his medicine? So, you find that we reduce on other things. I have to make sure I buy medicine that will last him a month (FCG6, Single mother).

This single mothers' experience illustrates how families of substance-dependent youth often forgo other daily life necessities like buying enough food in their quest to meet the medication and health needs of the child in recovery from addiction. The situation is dire for families experiencing financial hurdles like this lone mother's.

FCG21, a mother who was also experiencing financial challenges after her salon got broke due to caregiving responsibilities and poor business during the pandemic, got a loan to help her solve her financial problems as well as support her cannabis-abusing son, his wife, and child all of whom were under her custody. Although getting a loan was a short-term measure to cushion the financial difficulties, the burden of care was huge. It required a sustainable source of income, which many FCGs desired during the pre-pandemic and more so during the pandemic.

In alleviating their financial hardships, most FCGs leveraged the support of close family members such as other children. For instance, FCG3 engaged her daughter in selling merchandize (street vending) since their father was diagnosed with a heart condition and could not do taxing work. The primary responsibility fell on this female caregiver, who had to negotiate to be a mother, caregiver, and breadwinner for the entire family.

Some caregivers opted to end the manipulation and extortion by traditional and faith-based healers who wanted to make more monies during the pandemic by refraining from accessing such services (see FCG3's story on page 21).

To cope with the pandemic's challenge on household feeding and accommodation expenses, some affected families reduced the usual three meals per day to only one meal and resorted to finding much cheaper rented houses regardless of family size. As FCG8 notes, "During COVID-19, at work, they told us to stop going for a while. When we stopped working, we had challenges at home because we started eating once daily, around 18 h, and the young children would be problematic. So, we would find some foods like rice for them. The other issue was on rentals. We stopped managing to pay for rentals. We would stay 4 months without paying until we find some affordable apartment" (FCG8, Uncle). This account illustrates the precarious experiences that FCGs had when they were put on hold at work as a pandemic measure. They had to adjust their feeding and living arrangements to survive, revealing the shifting priorities that FCGs had during the summit of the COVID-19 pandemic.

Conversely, caregivers of youth with violent tendencies resorted to working on a shift basis to monitor the young adult better. FGC16, a widower and security guard, decided to change shifts because he feared that his cannabis-abusing son would harm his siblings when left unsupervised for a long time. He did this to ensure the safety of his younger children, who were often left home alone after the demise of their mother.

> He started becoming so violent, and he could even break all properties…since I am a single parent… It was challenging for me to take care of him because the moment I would leave him alone in that house, he could start beating the other children. So, I said, since I work at night, he might kill one of the…siblings (FCG16, Father & widower).

Despite having this strategy to cope with his situation, this widowed caregiver acknowledged that balancing work requirements with family caregiving was a highly stressful experience for him, and he wished that his wife was around.

A mother who also had safety concerns for her son with runaway tendencies devised a strategy to keep the son safe and reduce worrying about his whereabouts. FCG26 sent the son to her sister-in-law, whose house was in a wall fence, to prevent him from leaving home during the pandemic. She also did this to avert the stigmatizing sentiments of people in her neighborhood, who constantly insulted and mocked her son whenever he went to their yards.

> I was not free when he would trouble me a lot with his constant movements, he would go to other people's yards, and they would

> hurl insults and chase him, saying, go to your mother, you mad person, do not bring your madness here… So, there was a time I took him to my sister-in-law, where there is a wall fence so that he could stay there (FCG26, Mother & Widow).

Despite taking this move, her coping strategy was short-lived, as she disclosed later in her interview that "he stayed for a while and started troubling that he wants to come back home." This shows how disorienting caregiving for an emerging adult with addiction problems could be due to their unpredictable behaviors, a finding that has been widely cited in the extant literature on caregiving for adolescents and family members with substance use problems (59, 67, 68).

Similarly, to cope with his son's uncontrollable movements, a father sent his alcohol-abusing son to the village because he thought it was much safer in terms of low COVID levels and that the young person would not contract COVID even if they moved around as opposed to roaming the city where cases were high. His decision was with the view that the youth would come back to Lusaka after the pandemic had receded.

Furthermore, to keep his out-of-school and not-in-employment youth busy, one male caregiver engaged his son in agricultural activities to divert his focus from searching for and abusing substances. Doing this worked well for FCG30 because his son was interested in farming.

However, it is worth noting that although FCGs in this study employed ingenious coping strategies based on their complex situations, some problem-focused coping strategies were to the detriment of family members supporting the caregiver. For instance, one widowed mother (FCG9) engaged the daughter to work on her behalf as a maid so that she could focus on her caregiving responsibilities for her son with cannabis use problems. Unfortunately, this approach resulted in her daughter dropping out of school. This FCG inadvertently had two children out of school due to addiction in the family. As Mikulić and associates (69) note, addiction care is a family burden that "affects many aspects of family members' lives" [(69), p. 2], in this case, the educational prospects of FCG9's daughter.

## Discussion

Forgone healthcare is a critical issue that affects millions of people worldwide. It refers to the healthcare services people do not utilize or access despite the need, for various reasons including cost, accessibility, and personal beliefs. The literature shows that forgone healthcare is prevalent among vulnerable individuals with chronic conditions (16, 70), including people with addiction problems (71). Findings in the current study reveal how routine care for young adults with SUDs was hampered by structural and personal factors, resulting in an underuse of SUD recovery services in this group. For instance, there was a considerable change in the financial situation of most FCGs during the pandemic, and this was for the worst, where they experienced an unprecedented deterioration in their incomes. Even before the pandemic, the economic challenges and huge out-of-pocket bills that most family caregivers had resulted in foregone healthcare due to a lack of transportation fees and funds to purchase expensive psychotropic drugs. During the pandemic, some pharmacists extorted prices due to limited supply and increased demand, challenging medication access.

Research conducted by Haley and colleagues in Spring 2021 (72) shows that parental caregivers with low incomes experienced increased difficulties in affording the required care during the pandemic than those with higher incomes. These authors argue that "Challenges accessing and affording health care among parents with low incomes could compound the other hardships they were experiencing before the pandemic and that were likely exacerbated by the crisis" [(72), p. 2], a scenario similar to that of carers in Zambia. This infers that parental income was affected during the pandemic leading to forgone healthcare for many. Similarly, forgone healthcare was reported in the US in the initial phase of the pandemic (73). Financial concerns and the fear of contracting the virus were among the reasons for foregoing care resulting in missed administrations of prescribed medications.

Contrary to the findings in the current study, Markoulakis et al. (66) found that caregivers of youth with mental health and addiction problems in Canada forwent care due to the perceived unavailability of services and as a way to keep their young person out of risk through not allowing them to visit the hospital. Their findings reveal differences in caregivers' experiences between those in developed countries and those in LMICs like Zambia. For instance, FCGs of youth with SUDs in Zambia, despite facing the imminent risk of contracting the virus, sought addiction care for their adolescents and young adults by following the requirements for accessing mental healthcare during the pandemic. Despite these differences in experiences, financial constraints due to job losses were reported in the study done by Markoulakis and colleagues and in the current study, posing a challenge in the capacity of these family carers to support their young adults. This illustrates the cross-cutting and perversive impact of financial hurdles on the treatment and care of youth with addiction problems in the pandemic context, resulting in forgone healthcare for some.

The poor addiction healthcare help-seeking behaviors and perceptions, particularly among young adults with treatment-elusive and runaway tendencies, compounded caregivers' problems, created a constant burden for the family caregivers, and resulted in forgone healthcare. Pham et al. (74) also established forgone healthcare among in-school and out-of-school adolescents with mental health concerns in Indonesia. For those in school, perceptions of their problems resolving with time, and the fear of doctors' reports made them forgo healthcare, whereas those out-of-school were affected by accessibility factors such as the cost of care and lack of transport, and limited knowledge on available services. Their findings on what influenced forgone healthcare among young adults depart from those in the current study where most youth forwent care due to poor cognition emanating from addiction, and a lowered sense for the need for healthcare among treatment-elusive youth with chronic SUDs.

This scenario resulted in family caregiver's perceived far-fetched recovery of the youth and increased their frustrations about the futility of their efforts when the young person relapsed. Consequently, FCGs ditched help-seeking on behalf of their young adult. Also, the highly fragmented child and adolescent mental health system and poor continuum of mental health care in Zambia exacerbated forgone healthcare for this population. Most young adults with SUDs fell through the cracks of a fragile and uncoordinated mental health care system. These barriers to care and their impact on forgone healthcare were also established by Tsuzaki and Taira (75) among medicare beneficiaries with non-COVID related illnesses. For them, factors

such as availability of appointments for telehealth care, COVID-19 vaccination status, region, race, age, sex, and ethnicity influenced forgone care during the pandemic. Their findings reveal that forgone healthcare is influenced by different factors in different contexts, signaling the importance of context-specific interventions.

Taken together, reviewed studies on forgone healthcare all show financial challenges as a significant barrier to care during the pandemic. With the loss of work during the COVID-19 pandemic, most families missed or postponed care due to costs (76).

Regarding the lived experiences of family caregivers given herein, this paper argues that the COVID-19 pandemic deepened the old constraints and brought new challenges for FCGs of emerging adults grappling with addiction. It is noteworthy that the caregiver burden existed before the pandemic in terms of financial challenges, hopelessness, work disruptions, and loss of jobs due to missing work to attend to caregiving responsibilities. However, as noted earlier, the loss of employment was worsened by the COVID pandemic due to stay-at-home orders and the closure of businesses. Since most FCGs are in the informal sector, they were gravely affected. Therefore, as with a number of studies on forgone healthcare, findings of the current study confirm that the COVID pandemic exacerbated the initial challenges experienced by FCGs, more so carers of young addicts.

Although the COVID-19 crisis is over and we are in a (post) pandemic era, the caregiving burdens of these vulnerable family carers, pre-existed the pandemic, are likely to continue and have been exacerbated by the pandemic. This is because of the unabated structural and personal impediments to mental healthcare in Zambia. As in the past, minimal support continues to exist for FCGs of youth with addiction problems and other mental disorders due to a poor understanding of mental health problems (31, 32, 38), the highly stigmatized nature of addiction and the perceptions of addiction as a moral failing (77). The study revealed that most parents and guardians need financial, emotional, instrumental, informational, and respite support. In addition, the Zambian economy is still experiencing the adverse effects of the pandemic, and economic recovery is at a snail's pace. For most FCGs whose livelihoods were affected during the peak of COVID-19, their financial situation remains critical even in the (post) pandemic era, making access to needed healthcare services and treatment regimens an ongoing challenge.

Young adults with chronic untreated SUDs continue absconding from home, engage in risky behaviors such as heavy abuse of alcohol, cannabis, and other concoctions of harmful drugs, and remain out of school and employment, creating more burdens for their FCGs. The easy availability, accessibility, and affordability of harmful substances in Zambia (10) depicts the unaltered and continued use of substances. This contradicts European scholars' assertions, "We may expect decreased levels of substance use in the short term due to decreased availability and affordability." [(78), p. 2]. While this holds for most developed countries where low availability, skyrocketing prices, and financial impediments associated with the pandemic resulted in the decreased use of substances, the Zambian scenario offers a different perspective and extends our understanding of changing patterns of substance use in pre, during, and post-pandemic times.

Interestingly, most young adults in the current study were unaffected by school closures resulting from pandemic measures. This is because they were already out of school before the pandemic. Moreover, their dropping out of school was attributed to the abuse of alcohol and cannabis. Being out of school during the pandemic meant the burden of care was more for FCGs, who had to juggle caring for their young adult in the home and dealing with disruptive behaviors and other responsibilities. This shows that the pandemic was not responsible for the change in educational attainment for young adults who were not in school before the onset of the COVID-19 pandemic. Moreover, even during the May to August 2022 interviews, most FCGs reported that their child was not in school.

While both male and female caregivers had similar experiences of caregiver burden, emotional distress, work disruptions, and financial challenges, nuanced differences were also evident in these carers' experiences. For instance, lone female caregivers who were single, divorced, widowed, and those with estranged partners desired more physical and financial support. In contrast male caregivers wanted instrumental support with activities of daily living. Concerning SUD stigma, male FCGs responded to stigmatizing sentiments from community members with food for thought questions to the perpetrators, whereas female FCGs used more of emotional statements justifying that they never envisaged their children in such a predicament of having SUDs (see page 24). Regarding decision-making in the healthcare setting and their relationships with healthcare professionals, male caregivers were more assertive than female caregivers. Males actively engaged the healthcare personnel, asked critical questions about the youth's diagnosis and care, whereas most females often heeded to practitioners' advice as experts. This finding reflects the sociocultural context of the study where males are expected to take lead in decision making while women assume the listening role. In the same vein, when dealing with their youth's problematic behaviors, male FCGs were restrictive and expressed authoritarian attributes as opposed to female FCGs who were more nurturing. For example, male carers used physical restraints like chaining their youth with runaway tendencies to curtail their movements and keep them indoors.

Although family caregivers experienced multiple challenges, they also found ways of coping. Problem-focused coping was the most predominant among them. As earlier noted, perceptions of a far-fetched recovery made some FCGs forgo healthcare at some point. Despite this, FCGs were still actively searching for help from different sources on behalf of young adults, such as faith healers, spiritualists, traditional healers, and herbalists. The aim was to secure the recovery and return to normalcy of the affected young adults.

Overall, steps were implemented to assess the quality of the primary data, encompassing procedures to ensure and uphold the trustworthiness of the qualitative findings presented in this paper (79). This procedure included peer reviews conducted by supervisors in the quality control procedures. These reviews ensured the appropriateness of the study by providing feedback on various aspects such as literature review, data collection methods, data management processes, data analysis procedures, and research findings. Member checking was utilized to ensure rigor and establish the credibility of the research (80). Before the second interview, caregivers could review the transcripts and confirm if the transcribed content accurately reflected their interview discussions. Following the second interview, transcripts were shared with participants with access to working emails and smartphones for further verification. Coherence was further ensured by re-listening the recorded interviews and comparing them with the transcripts. Furthermore, sensitivity to the study context was considered throughout the study process. Having the lived experience as a Zambian national, and the adherence to the values and

norms of Zambian society helped design the study and my positionality and cultural sensitivity as a researcher.

## Limitations

Since the study's findings are based on the lived experiences of a small purposive sample of FCGs of adolescents and young adults with SUDs from Kanyama General Hospital's Mental Health Unit, the results cannot be generalized. The carers' experiences in this study may differ from those in other settings and caregivers not attending outpatient SUD recovery services from KGH. However, this study provides an in-depth understanding of FCG's experiences and the meanings they attach to them. Since the research was conducted in an urban setting in Zambia's capital, Lusaka, there is a need for future studies to consider rural FCGs. A longitudinal study over a longer period would also aid in gaining detailed insights into the experience of FCGs of young people with addiction problems over an extended period, particularly in LMICs, which lack such studies.

Being a study that involved in-depth face-to-face semi-structured interviews, the possibility of response bias due to my presence as the interviewer was inevitable. As Thomas et al. (81) note, the existence of an observer (such as a researcher) causes narrators to present altered accounts of their experiences compared to the anonymity provided by online storytelling. With this, future studies can also consider the alternative of getting the lived experiences of FCGs through online narratives.

## Implications for policy and practice

The study findings presented herein have implications for SUD caregiving, youth mental health legislation, policy, and services. Regarding the work disruptions encountered by FCGs in this study, there is an urgent need for flexible leave programs for FCGs employed in the formal sector, enabling them to prioritize caregiving without worrying about missed workdays. Since many FCGs were engaged in informal employment, there is a need for targeted social protection policies and interventions to ensure their well-being. For instance, integrating them into the Social Cash Transfer program as beneficiaries would alleviate the financial challenges experienced by these caregivers.

The caregivers' narratives also reveal a necessity to enhance the accessibility of evidence-based care and assistance services for caregivers and their young adults. This involves expanding the availability and affordability of substance abuse treatment centers. In addition, the manipulation and extortion experienced by caregivers call for developing legislation to govern the practices of traditional and faith-based healing practitioners, who are among the key service providers in the Zambian mental health system.

Furthermore, the logistical and in-person barriers to healthcare access experienced by FCGs calls for the consideration of telehealth in SUD recovery services in Zambia. Moreover, telehealth treatment is seen as the "new normal" in addiction care worldwide, where outpatient care is envisaged as hybrid. That is the use of telehealth and in-person services. During the COVID-19 pandemic, telemedicine

has been seen to minimize the risk of virus transmission while eliminating various logistical obstacles tied to in-person treatment services (82).

While most countries especially developed countries have responded to challenges in addiction care during the pandemic using telehealth and other robust approaches, Zambia is yet to implement comprehensive telehealth services (83) for SUD recovery services for young adults and their family caregivers. A Lack of virtual care for treatment-elusive youth with chronic SUDs poses a double burden for FCGs. Often, carers have challenges engaging their young adult in in-person outpatient services. In developing nations like Zambia, the scarcity of rehabilitation resources leads to the chronicity of SUDs and, consequently, a higher caregiving burden.

It is worth noting that individuals contending with addiction problems are high-risk groups that need workable interventions to support their recovery journeys in the post-COVID era.

Given the unpredictable pandemic, including those that will emerge, SUD recovery services for young adults in LMICs need to urgently adapt innovative technologies like telehealth and other locally feasible approaches (84) to avert disruptions to the continuity of addiction care (82) brought about by the reported treatment-elusive tendencies of young adults with SUDs. Doing this will fill the gap when young people and their families cannot attend face-to-face consultations. Due to their high vulnerability socially, economically, and health-wise (78), there is a need for tailor-made addiction care plans that are context-specific in the post-pandemic era for emerging adults grappling with substance use disorders.

The impact of forgone healthcare on individuals cannot be overstated, as it can lead to severe health complications, decreased quality of life, and even mortality. Additionally, society may experience lower productivity, higher healthcare costs, and reduced economic activity due to the inability of individuals to receive healthcare services.

Furthermore, putting off care for young adults grappling with SUDs has adverse outcomes for their recovery trajectory. More coordination of services among different providers (public, private, traditional medicine, and faith-based healing) is urgently needed to deal with the fragmentation of child and adolescent mental health services and challenges in the continuity of care.

To minimize forgone healthcare, particularly in a pandemic context and beyond, the Zambian government and other key stakeholders should develop robust mental health services and support for affected family caregivers and care recipients. This may involve implementing policies to reduce healthcare costs and increase mental healthcare funding and supply of psychotropic medications. Reducing healthcare costs through measures such as price transparency and negotiated drug prices would be an approach that might cushion the impact of out-of-pocket payments borne by family caregivers. Healthcare providers should offer more accessible care options by strengthening community mental health services and bringing them closer to the people. Telemedicine and other innovative technologies may also help to reduce forgone healthcare. This will help address the problem of relapse and the gap between healthcare institutions and the community.

To tackle the stigma experienced by FCGs, the government and critical stakeholders should implement awareness programs to educate and sensitize community members on mental health problems,

including addiction. Doing this will improve the mental health literacy of the population and reduce stigma toward persons and families affected by addiction, commonly known as a family disease (69). Also, the Zambian government should consider mass recruitment of mental health social workers in public health facilities, who will act as a bridge between families in the communities and healthcare facilities. Follow-up for treatment-elusive youth will be much easier when social workers are engaged as healthcare facilitators for this medically vulnerable population.

In addition, the experiences of family caregivers necessitate their inclusion in the policy formulation process. This is because FCGs' voices are largely missing in policymaking in Zambia. Including them would lead to the creation of policies that address the actual and not perceived needs of caregivers of young adults with SUDs.

Also cardinal, and a much more feasible and less expensive approach is for the creation of spaces (in healthcare facilities and the community) where caregivers can share their lived experiences and encourage one another. Creating such platforms for caregivers would reduce feelings of isolation and stigma and at the same time lead to more SUD caregivers who are often a hard-to-reach population being reached by available services thereby mitigating forgone healthcare. This is because although several caregivers acknowledged that there were other FCGs in their situation due to the prevalent SUDs among youth in the communities, none of them outrightly suggested having a community of caregivers to share notes. This might be due to internalized stigma and the marginalization of FCGs of persons suffering from addiction in Zambia, something that is considered as a personal misfortune. Although this was the case, most FCGs made recommendations for government support to other caregivers like themselves especially with the need to regulate and curb the sale of harmful substances that were reportedly cheap and easily accessible to the youth.

## Conclusion

Based on the lived experiences of family caregivers of emerging adults grappling with addiction, the present study shows why FCGs forwent care for this medically vulnerable group. Forgone healthcare was due to factors such as treatment-elusive tendencies among some young people with SUDs, lack of family support, financial challenges, FCGs' perceptions of a far-fetched recovery, manipulation and extortion of healthcare fees by some traditional and faith healers, challenges in medication access due to border closures during the pandemic, and the youth's negative outlook on COVID, perceptions of being unsusceptible to the virus and the consequent non-adherence to health interventions.

It is worth highlighting that forgone healthcare before, during a crisis, and beyond is a complex problem requiring a multifaceted approach. By expanding insurance coverage to cater to those in the informal sector (like most FCGs), reducing healthcare costs, and improving healthcare access, policymakers can ensure that patients and their families receive the care they need when they need it without incurring undue financial burdens or other negative consequences. Therefore, the current study's findings highlight the need for continued support for FCGs of young adults struggling with addiction in Zambia and other countries with similar socioeconomic contexts.

## Strengths of the study

Among the strengths of this study is the sample representativeness in terms of the inclusion of male caregivers, an uncommon phenomenon in most studies on addiction caregiving for young adults in Sub-Saharan Africa. A plethora of studies only capture the experiences of mothers. This study had a total of 11 male caregivers which included fathers, uncles, a brother, and a husband. Having this representation of the male caregivers in a patriarchal society like Zambia, where family caregiving is highly perceived as a preserve of women is one of the strengths of the study, which revealed nuances of addiction care for young adults with problematic substance use.

The longitudinal design of the study (albeit short-term due to the nature of the main study) where two interviews were conducted in a space of 4 weeks provides valuable insights into the long-term effects of SUD caregiving on family caregivers. In addition, getting the retrospective and current experiences offers a holistic understanding of FCGs' experiences over time.

The study's policy and practical implications are also a strength of the study, including the study context where studies on forgone healthcare are limited. For example, findings on the manipulation and extortion of FCGs by traditional and religious healers as influencing forgone healthcare add to the addiction caregiving literature. These findings depict the importance of understanding the caregiving context and its differential impact on the lived experiences of FCGs thereby resulting in a comprehensive analysis of forgone healthcare.

## Data availability statement

The datasets presented in this article are not readily available because the datasets in this qualitative study cannot be shared in their original form due to confidentiality concerns. Requests to access the datasets should be directed to IK, ireenkangwa1@gmail.com.

## Ethics statement

The studies involving humans were approved by Humanities and Social Sciences Research Ethics Committee (HSSREC) of the University of Zambia and Lingnan University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

IK carried out all aspects of the study, from design, data collection, analysis, and interpretation of findings, and drafted and submitted the manuscript.

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## Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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## Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2024.1250608/full#supplementary-material

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