The Modern Day Asylum: A Mad Studies Informed Approach to Understanding De-Institutionalization, Madness and Chronic Homelessness

L’asile des temps modernes : une approche éclairée par les études de la folie pour comprendre la désinstitutionnalisation, la détresse mentale, les traumatismes et l’itinérance chronique

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Abstract

Background: The impetus behind the deinstitutionalization movement that began in the 1950s was to improve the wellbeing of institutionalized people as well as improve choice and access to inclusive community-based care. However, as large-scale institutions were closed, community-based alternatives were not added to meet the demand. This research looks at the experience of chronic emergency shelter users as an example of the ongoing systemic spatial segregation of people which was previously experienced in asylums. Drawing from some of the key features of Mad Studies, we utilize the experiences of chronic shelter users to posit enhanced approaches and supports to community-based interventions beyond the model of spatial segregation, which we argue is currently employed through direct and indirect measures. Approach: We conducted a cross-sectional study utilizing 300 survey interviews with chronically homeless people in Calgary, Alberta, Canada. Data was primarily quantitative but space for some qualitative answers were included. Analysis includes descriptive statistics, correlations, and regressions. Results: Participants reported high rates of trauma and system cycling, which were often inter-generational and starting in childhood. Troubling rates of self-identified “mental illness,” and mental health crises including suicide attempts and self-harm, and very limited success in accessing supports emerged. Results show that shelters and current housing models frequently replicate the segregation, confinements, control and surveillance of the asylums of the past which fail to meet individual needs and desires. Conclusion: Chronic homelessness and subsequent shelter use is the present reality of deinstitutionalization for many. Current attempts to fill gaps in the system of care replicate institutional care in various formats, and have halted progress towards the actualization of deinstitutionalization. Alternative responses require us to challenge the medicalization of homelessness as “mental illness.” Interventions including housing
Résumé

Contexte : L’impulsion derrière le mouvement de désinstitutionnalisation qui a commencé dans les années 1950 était d’améliorer le bien-être des personnes institutionnalisées ainsi que d’améliorer le choix de soins communautaires inclusifs ainsi que leur accès. Cependant, à mesure que les grandes institutions ont été fermées, des ressources communautaires n’ont pas été ajoutées pour répondre à la demande. Cette recherche examine l’expérience des personnes utilisatrices chroniques de refuges d’urgence comme un exemple de la ségrégation spatiale systémique continue, qui était auparavant vécue dans les asiles. En nous appuyant sur certaines des caractéristiques clés des études de la folie, nous utilisons les expériences des personnes utilisatrices de refuges pour proposer l’amélioration des approches et du soutien destinés aux interventions communautaires qui dépasse le modèle de ségrégation spatiale, qui, selon nous, est actuellement utilisé par des mesures directes et indirectes. **Approche** : Nous avons mené une étude transversale en utilisant 300 entrevues avec des personnes en situation d’itinérance chronique à Calgary, Alberta, Canada. Les données étaient principalement quantitatives, mais un espace était prévu pour certaines réponses qualitatives. L’analyse comprend des statistiques descriptives, des corrélations et des régressions. **Résultats** : Les participants ont signalé des taux élevés de traumatismes et d’enjeux de navigation du système, souvent intergénérationnels et commençant dès l’enfance. Des taux troublants de « maladie mentale » auto-identifiée et de crises de santé mentale, y compris des tentatives de suicide et d’automutilation, et un taux de succès très limité pour avoir accès à du soutien ont également émergé. Les résultats montrent que les refuges et les modèles de logement actuels reproduisent fréquemment la ségrégation, le confinement, le contrôle et la surveillance des asiles du passé et ne répondent pas aux besoins et aux désirs individuels. **Conclusion** : L’itinérance chronique et l’utilisation subséquente des refuges sont la réalité actuelle de la désinstitutionnalisation. Les tentatives actuelles pour combler les lacunes du système de soins reproduisent les soins institutionnels sous divers formats et sont venues stopper les progrès vers l’actualisation de la désinstitutionnalisation. Les autres options pour répondre à cette situation nous obligent à remettre en question la médicalisation de l’itinérance comme forme de « maladie mentale ». Les interventions, y compris les programmes de logement, doivent être axées sur la guérison des traumatismes et inclure les voix d’experts et leurs expériences vécues.

**Keywords**

Deinstitutionalization; Mad Studies; Homelessness; Trauma; Community Care

Introduction

Over the course of a year, emergency shelters in Canada will see more than 230,000 people (Gaetz et al., 2014). Research on adult shelter utilization in Calgary, Alberta, Canada shows that 86% of people will experience “transitional” homelessness, or will access an emergency shelter.
only once, while 12% will access a shelter repeatedly over the course of several years (episodic homelessness). A smaller group, approximately 2%, considered chronically homeless, will stay in shelters for several years due to very complex and unmet physical, social, emotional, and mental wellness needs (Kneebone et al., 2015). Chronic shelter users also tend to cycle through multiple institutions including hospitals, jails, treatment programs, and then back to shelters which exacerbates what are labelled “psychiatric crises” (Canham et al., 2018).

Institutional care has a long history of segregating those who have been called “lunatics,” “the insane,” or the “mentally ill” (Reaume, 2002). Deinstitutionalization is understood as the release of previously excluded groups from large-scale psychiatric hospitals into small scale settings within the community (Dear & Wolch, 1987). Prior to the Second World War, psychiatric institutions and hospitals struggled with overcrowding, fiscal restraints, and demonstrated inhumane treatment towards residents. The movement to deinstitutionalize and the subsequent move to community care is widely problematized in the field of disability studies. A lack of low barrier community supports and affordable and safe housing are identified as significant issues that have occurred since deinstitutionalization (Reaume, 2002).

Our research team met with 300 people living in chronic homelessness in Calgary, Alberta, Canada over the course of three months. We led survey interviews to understand their lifelong experiences of trauma, homelessness, and system cycling. Using a Mad Studies approach to analysis, we argue our results show that emergency shelters, specifically for those who live in chronic homelessness, have emerged as a modern day asylum for people who struggle with complex health and social needs. We also argue that processes to exit homelessness, including those grounded in principles of Housing First, are highly medicalized and people in homelessness continue to be pathologized as sick and deviant.
We conclude that for reform, the actual and symbolic walls of modern-day asylums must be broken down. Beyond the segregation, confinements, control, and surveillance of the modern-day asylum (exemplified by the experiences of chronic shelter users) we show the possibility of community-based housing programs (i.e., Housing First) as a model which challenges current systems, and attempts to privilege the needs and voices of those who have been through the system (Beresford, 2020).

Background

Madness Studies, De-Institutionalization and Homelessness

This study draws from some of the key tenets of Mad Studies informed research and seeks to “embrace a body of knowledge that has emerged from psychiatric survivors, Mad-identified people, anti-psychiatry academics and activists, critical psychiatrists and radical therapists….,” (Menzies et al., 2013, p. 337). Based out of the psychiatric survivor movement Mad Studies takes inspiration from subjectivities, embodiments, narrative, experiences, and aspirations of those who have been a part of institutional psychiatric systems (Sweeney, 2016). The experiences of those who have been part of the psychiatric system are used as a platform to analyze the ongoing spatial segregation which marks the modern day asylums frequently faced by people who are labelled “mentally ill.” Deinstitutionalization is identified by Mad Studies scholars as a form of social oppression, and the “urban ghettoizing of ex-patients under the guise of ‘downsizing’ and ‘re-integration’” (Menzies et al., 2013, p. 143) as a promoter of social and economic inequity.

There is significant debate around the ways that individuals with a psychiatric history self-identify, including terms such as patient, consumer, ex-patient, client, ex-inmates, the psychiatrized, user, or psychiatric survivors to challenge negative images and treatment of
former psychiatric patients (Reaume, 2002). For the purpose of this paper, we use the terms “mad,” “madness,” and “mad people,” as “allies and social critics” (Menzies et al., 2013) of the dominance and determinism of psychiatry. We hold a collective respect for the value of mad people, and recognize the importance of privileging mad thought. In our analysis, we refer to people with “psychiatric histories,” and “psychiatrized citizens” in place of people with “mental illnesses,” terms used by Reaume (2002), and Menzies et al. (2013). We refer to experiences of psychiatric crises or mental distress to differentiate this experience from the overall experience of madness (Spandler et al., 2015).

It is crucial to note that the descriptors used in this paper are not those of the participants or of the interview survey conducted, as these are not the terms that are commonly used amongst chronic shelter users. The identification of “mental illnesses” and specific diagnoses were used as terms of shared understanding amongst those who completed the interview surveys. The use of the politicized language of madness in this paper reflects the research teams’ politicized views of systems and ideologies we seek to challenge.

**A History of Segregation, Confinement, and Control**

Institutionalization has a long history in the Western world. The practice of moving people to segregated environments has served to control, expel, silence, disempower and erase people in the name of health, training, and betterment of the population (Abbas & Voronka, 2014; Malacrida, 2015). This form of social control is used to regulate, stop, and prevent “deviance.” During the “asylum era” from the mid 1850s to the 1970s, or what Foucault (1965) referred to as “the great confinement,” prisons, workhouses, colonies, and asylums have shaped understandings of non-conforming bodies and minds and the notion that those who do not fit the
norm need to be controlled (Abbas & Voronka, 2014). In what Goffman (1961) called the “total institution,” we see mad people controlled, confined, monitored, surveilled, categorized, and typified by “experts.” The people residing in the institutional systems became emblematic of a state of exception, and in need of treatment to re-enter society. Goffman (1961) notes however, few people escape the total institution.

The institution itself, in its existence as all of the above things, represents a firm grounding in practices of spatial segregation and exclusion. The removal of mad people to institutions out of sight of the general population elicits images of locked doors, high walls, forests, water, and moors. Often set in rural locations, traditional institutions are “away” (Park & Radford, 1999). The large scale asylums of Alberta are reminiscent of the spatially segregated classic Kirkbride institutions of the second half of the nineteenth century, which existed in secluded areas with large grounds and classic architecture.

Two of the largest institutions in Alberta are Ponoka and Michener Centre. The Ponoka center has transitioned through several name changes including: The Alberta Mental Hospital, Alberta Hospital for the Insane, Provincial Mental Health Hospital, Ponoka Mental Hospital, and Ponoka Insane Asylum. Its current name is the Centennial Centre for Mental Health and Brain Injury, and it is located in a small town in central Alberta. This was the primary mental health institution which opened in 1911 (Leung, 2021) and housed over 1600 people in the 1940s. Ponoka, is linked with eugenic practices against residents. Michener Centre, originally The Provincial Training School for Mental Defectives, opened in 1923 in the town of Red Deer and housed up to 2000 residents. The Michener Centre has a long and “sordid” (Wingrove, 2013) history of sterilization and mistreatment of people with intellectual disabilities and is what Malacrida (2015) calls “A Special Hell.”
While both institutions have undergone transformations in service delivery, critics argue that issues of overcrowding and understaffing perpetuate issues of social isolation, neglect, and deprivation (Malacrida, 2015). Their continued existence increases the risk of a “reinstitutionalization movement” should the political will emerge. Their continued existence is also argued to be because large-scale institutions in smaller centres are primary employers that create job opportunities. They also continue to exist because of the historical absence of community-based alternatives.

Deinstitutionalization

Following WWII, increasing attention was paid to the poor treatment of patients in psychiatric institutions (Rose, 1979). The collapse of the asylum system was framed in a community mental health movement (Shimrat, 2013). For individual consumers of mental health services, the new, market driven, community-care system was supposed to provide better options (Macdonald et al., 2018). The rationale supporting deinstitutionalization was to improve choice and autonomy, reduce restrictions, and improve human rights. It was believed that shifting from institutional care toward home and community-based care would result in reduced costs and improved health, wellbeing, and societal acceptance (Lesage, 2000). It was argued that institutions increase fear and stigma toward those considered different, as they are made “invisible” or removed from the public eye (Ben-Moshe et al., 2014).

Mad Studies scholars argue however, that the wholesale closure of institutions without appropriate community-based care has exacerbated the social inequity and stigma of institutional survivors. Most institutional and bed closures occurred in the 1970s and 1980s when there was a 62% reduction in psychiatric beds (Sealy & Whitehead, 2004). This coincides with the
psychiatric survivor movement which started in the 1960s and 1970s as relations shifted and evolved between psychiatry, society, the individual, and the state (Menzies et al., 2013). “By deinstitutionalizing patients, the government was able to save a substantial amount of money and present society with the belief that this was being done under the guise of humanitarian care” (Niles, 2013, p. 68).

The promises of community care that accompanied deinstitutionalization have not been realized. Once discharged, former residents did not receive improved quality or better access to services, but have been subjected to chronic underfunding, inadequate, poor quality and poorly coordinated social supports that have defined this ostensibly progressive movement (Macdonald et al., 2018; Menzies et al., 2013). “Although funding was provided in the community, it was provided at levels far below that needed to successfully support these individuals’ needs” (Niles, 2013, p. 75). Since this time, many people have been shown to struggle to adapt to life in the community (Macdonald et al., 2018), often with limited social and familial supports (Menzies et al., 2013). Out of the previous institutions, people who are chronically homeless cycle through other institutions and institutional systems including foster care, hospital, jail, treatment programs, and back to shelter.

Homelessness

The 1980s in Canada marked the beginning of several decades of reduced government funding for social programs. As neoliberalism and a preoccupation with reducing deficits and cutting costs grew, so did cuts to social programming including affordable housing programs. Deinstitutionalization and concurrent neoliberal approaches created a “perfect storm” which some researchers argue is responsible for the exponential increase in homelessness in Canada between the 1980s and 2000s (Donnan, 2014).
Academics and researchers have a long history of arguing an inherent relationship between homelessness, poor health, mortality, and “mental illness.” Hwang (2001) showed that mortality rates for people experiencing homelessness are 2.3 to 8.3 times higher than the general population of the same age. Furthermore, people experiencing homelessness have higher than average rates of suicidal thoughts and suicide attempts (Hulchanski et al., 2009). “Mental illness” is cited as the most common reason people experiencing homelessness access emergency rooms, accounting for more than one-third of visits. The longer someone is homeless, the more complex their illness becomes (Hulchanski et al., 2009; Kneebone et al., 2015). Homelessness and homeless people have long been thought of as a problem of social disorder, with consistent arguments for the relationship between drug use, crime, incarceration, and homelessness (McNiel et al., 2005). These historical understandings mean that homelessness has become medicalized and pathologized and people living in homelessness are understood as sick, deviant, and dangerous (Dej, 2016). While many contemporary researchers are examining structural barriers and intersections between homelessness, gender, colonialism, class, and culture (Milaney et al., 2020; Smith et al., 2021), discourse, subsequent policy, and practice continue to be dominated by psy research and practices that are preoccupied with a medical expert model of homelessness and mental illness.

Multiple North American cities, including Calgary, Canada, have targeted strategies and plans to end homelessness (Pauly et al., 2013). Most of these strategies utilize research that shows that people (regardless of their needs) can be successful in maintaining housing in the community if they have access to housing with the proper supports (Goering et al., 2014). Those supports have been collected into a community-based intervention called Housing First (HF). HF is a program and a philosophy based on personal choice and “meets people where they are at” by
providing them with affordable housing and in-home supports without “proof” of sobriety or treatment compliance (Goering et al., 2014).

The processes to access these programs rely on assessments and surveillance approaches that force people to “prove” they are sick enough to qualify for a basic and universal human right to safe housing (Office of the United Nations High Commissioner for Human Rights, n.d.). Once housed, some are not able to sustain that housing due to inadequate supports to meet their unique needs and often return to homelessness (Clarke et al., 2019). Many HF programs require people to undergo an assessment of their “acuity” or severity of illness and risk for death, primarily because supply cannot meet the demand (Balagot et al., 2019). Once assessed, people are assigned a “score”; if your score is within the highest acuity range you should be prioritized for a housing program (Ratalade & Leo, 2019). A commonly used tool called the VI-SPDAT is widely used and measures “risk” including hospitalizations or emergency room visits, chronic diseases, co-occurring mental health and substance use disorders, and psychosocial risk factors. This tool has been criticized for being gender and racially biased (McCauley & Reid, 2020).

Despite a demand to enhance community care, and the vast amount of empirical research arguing that homelessness is a pervasive and complex issue (Donovan & Shinseki, 2013), people experiencing chronic homelessness continue to fall through the cracks of our public support systems. The research conducted by our team sought out the voices of long-term users of emergency shelters and the findings presented here are an effort to improve community-based care based on the voice of experience. We challenge the medicalization of homelessness and argue that shelters have become a modern day asylum, and processes to exit homelessness have become a form of spatial segregation, surveillance, and social control.

Methods
Data and Analysis

The research team conducted survey interviews with 300 individuals inside two emergency shelters. There were 88 questions focused on experiences of mental distress, traditional medical model diagnoses, systems use, and experiences accessing services. The survey was developed and approved with a community advisory committee that included representatives from 26 community agencies with an interest in better understanding where programs and policies are failing people. We also asked about experiences of childhood trauma using the Adverse Childhood Experiences survey. The ACE survey asks 10 Yes-or-No questions related to traumas that occurred before the age of 18. Participants are asked if they lost a parent to divorce, death, or incarceration; if they ever went without food, clothing or adequate care; and if a parent or family member had an addiction or “mental health” issue. They are also asked whether or not they witnessed or experienced family violence, neglect, or sexual abuse.

There are several limitations with the ACE survey. First, it assesses the total “types” of traumatic events, not the frequency or the severity. Second it has been criticized for being Eurocentric and racially biased (Smith et al., 2021). Finally, the ACE tool assigns a “score” based on the prevalence of childhood trauma. The research team recognizes the tensions in using standardized tools grounded in medicine in a study rooted in tenets of Mad Studies. Use of the ACE tool in our study was not to exploit psychiatric distress and to argue for medical intervention (as others have done), but rather to highlight the relationship between trauma and homelessness and to argue that medical approaches ignore experiences of trauma and reframe them as mental illness and social disorder.

Our intention was not to simply measure and report on mental distress, further substantiating the hegemonic medical discourse that homelessness is sickness. Rather, our intent
was to use the results to argue for a better “systems approach” or enhanced community-based alternatives grounded in the principles of Housing First, not the programmatic intervention itself. HF principles argue that anyone can sustain housing if the housing and supports are choice-based and designed to “meet people where they are at” rather than whether or not they are a “good fit” for a particular program model.

The study received ethics approval from the University of Calgary Conjoint Health Ethics Review Board.\(^1\) All participants volunteered and sat with a research assistant to go through the questions together. Data collection took place over the course of three months. Participants had experienced homelessness for at least six months and were over the age of 16. SPSS was used for analysis and the data presented here are in the form of descriptive statistics, correlations, and regressions. Although results are primarily quantitative, some survey questions included space for elaboration. We have included quotes where relevant; names were not collected so participant quotes include a pseudonym. Analysis of the data was guided by the following research questions: What are the systems use experiences of people living in chronic homelessness? What have been their experiences trying to access services? What can their experiences tell us about how to better respond?

**Results**

**Demographics**

One participant did not respond to all of the survey questions and was removed from the analysis, resulting in a total sample of 299. 72% of participants identified as men, 27% women

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\(^1\) Ethics certification number: REB1502194
and 1% (two people) transgender or two-spirited.\(^2\) 62% of respondents were white, 30% Indigenous and 8% from other racialized backgrounds. The average age in our sample was 47. 72% had been homeless for more than four years, and 27% of respondents reported being homeless for more than five years; however, the largest cohort (29%) had been homeless for longer than 11 years (Table 1). 27% reported having experienced homelessness more than five times in their lives (Table 2). One participant noted “I have lived here for so long, I have no idea how to live any other way” (Paul).

<table>
<thead>
<tr>
<th>Number of years experiencing homelessness throughout lifetime</th>
<th>6-11 months</th>
<th>1 year</th>
<th>2-3 years</th>
<th>4-5 years</th>
<th>6-7 years</th>
<th>8-9 years</th>
<th>10-11 years</th>
<th>&gt; 11 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>10</td>
<td>16</td>
<td>54</td>
<td>49</td>
<td>24</td>
<td>18</td>
<td>42</td>
<td>86</td>
</tr>
<tr>
<td>Percentage of respondents (N=299)</td>
<td>3.3%</td>
<td>5.4%</td>
<td>18%</td>
<td>16.4%</td>
<td>8%</td>
<td>6%</td>
<td>14%</td>
<td>28.8%</td>
</tr>
</tbody>
</table>

\(^2\) Two-spirited refers to a person who identifies as having both a masculine and a feminine spirit, and is used by some Indigenous people to describe their sexual, gender and/or spiritual identity (“Two-Spirit Community,” n.d.).
Table 2

*Number of episodes of homelessness throughout lifetime*

<table>
<thead>
<tr>
<th></th>
<th>Once</th>
<th>Twice</th>
<th>3 times</th>
<th>4 times</th>
<th>5 times</th>
<th>&gt; 5 times</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>79</td>
<td>47</td>
<td>43</td>
<td>28</td>
<td>21</td>
<td>82</td>
</tr>
<tr>
<td>Percentage of respondents (N=299)</td>
<td>26.4%</td>
<td>15.7%</td>
<td>14.4%</td>
<td>9.4%</td>
<td>7%</td>
<td>27.4%</td>
</tr>
</tbody>
</table>

*The Ace Survey*

Baseline surveys conducted in the 1990s using the ACE survey showed that 12.5% had an ACE score of four or higher (“Trauma Informed Care,” n.d.; Centers for Disease Control and Prevention, 2016a/b). In our study, 59.5% scored between four and 10 on the ACE survey. This is five times higher than the frequency of this score observed in the general population. Table 3 reports that the median ACE score among those in our survey was 4.2 for men and 5.0 for women.

Table 3

*ACE scores by gender*

<table>
<thead>
<tr>
<th></th>
<th>Average</th>
<th>Median</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>All genders* (N=299)</td>
<td>4.43</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Women</td>
<td>5.02</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Men</td>
<td>4.21</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
53% of women and 46% of men reported experiencing childhood abuse, and 52% of women and 22% of men reported being a victim of childhood sexual abuse. 55% lived in fear of physical violence and almost 40% lived in a house where a family member had a medical diagnosis of depression, mental distress and/or attempted or committed suicide. The most common ACE was having a parent with an alcohol or drug addiction (70% of women and 63% of men). One woman said “I don’t want to be here [shelter]…if there was anywhere else I could go, I would. It’s not safe for me here…I have never really felt safe” (Mary).

Table 4

*Including one transgender and one two-spirited respondent

<table>
<thead>
<tr>
<th>Variables</th>
<th>Years Homeless Score Coefficients</th>
<th>Times Homeless Score Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE score</td>
<td>.128*</td>
<td>.098*</td>
</tr>
<tr>
<td></td>
<td>(.050)</td>
<td>(.044)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------</td>
<td>---------</td>
</tr>
<tr>
<td>Age</td>
<td>.054*</td>
<td>-.025*</td>
</tr>
<tr>
<td></td>
<td>(.012)</td>
<td>(.011)</td>
</tr>
<tr>
<td>Male</td>
<td>.180</td>
<td>.263</td>
</tr>
<tr>
<td></td>
<td>(.294)</td>
<td>(.256)</td>
</tr>
<tr>
<td>Indigenous</td>
<td>.587</td>
<td>.597*</td>
</tr>
<tr>
<td></td>
<td>(.307)</td>
<td>(.268)</td>
</tr>
<tr>
<td>Children</td>
<td>-.338</td>
<td>-.163</td>
</tr>
<tr>
<td></td>
<td>(.271)</td>
<td>(.236)</td>
</tr>
<tr>
<td>Children in respondent’s care</td>
<td>-1.933*</td>
<td>-.747</td>
</tr>
<tr>
<td></td>
<td>(.904)</td>
<td>(.789)</td>
</tr>
<tr>
<td>Number of physical health diagnoses</td>
<td>.005</td>
<td>.090*</td>
</tr>
<tr>
<td></td>
<td>(.046)</td>
<td>(.040)</td>
</tr>
<tr>
<td>Social support</td>
<td>.105</td>
<td>.140</td>
</tr>
<tr>
<td></td>
<td>(.271)</td>
<td>(.236)</td>
</tr>
</tbody>
</table>

*Note. Standard errors in parentheses

* p < .05

**Institutions and Systems Use**

In the previous 12 months, 31% had been in a detox program, 23% in jail and 31% in hospital. Results show that systems interactions often started in childhood, for example, 42% of respondents had been in foster care. Four participants did not respond to the question and were removed from this analysis resulting in a sample of 295. An independent sample t-test revealed a significant difference in ACE scores between those who were in foster care and those who
weren’t: $t(293) = 7.07, p < .001$. Those in foster care reported a mean ACE score of 5.72 out of 10, while those not in foster care reported a mean ACE score of 3.46.

22% of people had been in a psychiatric facility, 44% of whom had been admitted multiple times. The times ranged from several days (44% of those admitted), several weeks (33%), several months (20%), and several years (1.5%). 26% had been discharged from these facilities directly to the street and 17% had been discharged to another facility or a jail.

One man talked about experiences trying to get support:

The system is crazy. To get into treatment you have to go to detox. You go to detox then have to wait six months to get into treatment and you are right back on the streets and right back in the lifestyle… It’s like they want us to fail. (Syd).

Another talked about his time in foster care: “I bounced around a lot [foster care] was not good for me. I ran away and ended up in shelters over and over again” (Mike).

Half of respondents indicated they received information about health, community services, and treatment programs from staff in emergency shelters. The half that did not receive this information said that they did not know whom to ask, were afraid to ask, felt they could not afford it, or did not have access to transportation to follow through. Of those who received treatment for “madness” in particular, over half indicated they did not get enough help.

In regards to working with shelter staff and accessing services many had mixed experiences: “The staff here are good. They care. But they don’t know everything and it is hard to know where to go for help. I have been turned away so many times I just don’t bother anymore” (Jeff). 62% of people had considered suicide and 39% had attempted it in their lifetimes. 29% of people had engaged in one or more forms of self-harm including cutting, burning or hitting themselves.
Discussion

The results from our survey show high rates of childhood trauma and mental distress for those experiencing homelessness (Hwang 2001; Hulchanski et al., 2009; Centers for Disease Control and Prevention, 2016a/b). A significant number of participants had histories of cycling in and out of systems and/or institutions, often starting in childhood, and moving back and forth from shelter to these systems appears to be a common experience. The number of people being admitted, then discharged from care back into homelessness shows a disconnect between public systems of support. The rates of violence, self-harm, suicide attempts, isolation and post-traumatic stress disorder are troubling. Another troubling finding was the very high rates of Indigenous peoples in chronic homelessness. Homelessness for Indigenous peoples in Canada can be traced to a long history of colonialism, and policies of assimilation that have forcibly segregated, isolated, and discriminated against Indigenous peoples for more than 100 years (Thistle, 2017). An analysis of these results has been published elsewhere, as this issue warrants a deep and critical analysis of the historical issues and implications (Smith et al., 2021).

While our data highlight that people in chronic homelessness have complex histories, our intention is not to reinforce the pathology of homelessness, rather to highlight, how even after several years of plans to end homelessness and a plethora of HF programming, our efforts continue to fail at providing people with supports that honour dignity, choice, or even safety.

Almost 30% of people we met reported being homeless for 11 years or longer and experiences of childhood trauma were highest for those who had been in foster care as children. A preoccupation with “acuity” masks the underlying trauma that may be at the root of “madness” and subsequent homelessness (Cronley, 2020). Some researchers have argued that the level of care provided for people once they are housed, despite an assessment of “complex needs” is not
adequate and the result can be a return to homelessness and exacerbation of trauma (Kertesz et al., 2017). For those who do maintain housing, HF participants typically undergo routine assessments of changes in their substance use, health, and use of public health and justice systems, often as a way to show cost savings (Friese & Wilson, 2021).

We continue to fall far short of the deinstitutionalization goals of the past, and our results demonstrate a pattern more fitting of the spatial segregation seen in formal institutions. Surveillance tools related to assessment of risk and acuity and continuous data collection to monitor “change” perpetuate pathology. It could be argued that the institutionalization of mad people continues, as people are cycling in and out of several institutions over the course of their lives, each of which has a potentially deleterious impact. Participants’ poor experiences trying to access meaningful supports likely exacerbate their trauma, and this is further evidence that the community-based alternatives promised during deinstitutionalization have not been realized. Emergency shelters appear to be the primary option for people in their efforts to seek care and have become, for people with very complex needs, the modern-day asylums.

By privileging the voices of mad experiences to identify gaps in social institutions which support chronic shelter use, we see the existence of modern day asylums which seek to segregate and disempower. This recognition compels us to consider this contemporary practice as a harbinger of the large-scale institutions of the not-so-distant past. Experiential data shows the need to challenge traditional medical interventions like assessments which have not been effective at meeting individual needs, and are not person-centered or grounded in personal choice. A more appropriate response is to expand existing networks of community-based health care, housing, and support programs that acknowledge the trauma people have experienced and continue to face while they are seeking supports, and acknowledge also that this trauma is at the
root of their mental distress and subsequent care needs. Being trauma-informed also means ensuring our responses are not continuously “re-traumatizing” people through the continuous cycling from system to system with no solution (Trauma Informed Care, n.d).

Continued dependency on assessments and diagnoses traps us in medical understandings and approaches focused on sickness rather than healing and are a surveillance technique that determines who is “allowed” access to housing. Pathologizing homelessness (whether in shelters or housing programs) has become of form of social control and allows for a continued preoccupation with the individual person and their role in their own wellness instead of focusing on the systems and structures that force people into a lifetime of vulnerability and dependency because they are failing to get better (Dej, 2016).

In addition to enhancements to formal services, the move from mental health supports to Mad-informed care needs to be recognized on a larger scale to reflect the priorities of Mad Studies approaches and understandings of deinstitutionalization, the valuation of difference, and the voice of experiential knowledge of this traditionally oppressed group. Mad people need to be present and visible in the consultation and re-shaping of the emergency shelter and housing systems. Relevant task forces could challenge power roles and assumptions that have frequently accompanied the development and implementation of services, and ensure the oft-silenced voices of service users are heard and listened to. To expand understandings of mental health, madness and the pathologizing/psychiatrizing of individuals also needs to be examined in this context. Arguments of inequity, social justice and the right to housing should be elevated. Finally, prevention efforts should focus on family-centered care: supporting families in their homes with healthy relationships and safety related empowerment to reduce the likelihood of foster care
involvement, continued childhood trauma, and the subsequent multi-generational and life course cycling in and out of multiple systems that our participants reported (Ko et al., 2008).

**Limitations**

Limitations include our sample. Only data from adults in emergency shelters was included. This excludes people in family shelters and domestic violence shelters who are also experiencing homelessness, but may have access to different models of service and care. We were also relatively unsuccessful in recruiting people who are “sleeping rough” which limits our discussion of the impact of street living and how it may be different than shelter living.

While our analysis quantifies people’s experiences, we are limited in what we can argue about the context of those experiences that a qualitative or narrative-based study could illicit. While we can understand histories, we cannot fully appreciate stories. Future research should prioritize rich qualitative stories in partnership with lived experts and include a focus on ways to engage people in Housing First programs that are trauma-informed and centred on the needs and wishes of tenants.

The ACE survey has its own limitations, as total numbers or “types” of childhood trauma are captured but they are weighted evenly. For example, witnessing violence is scored the same as experiencing childhood sexual abuse. The ACE survey also does not account for frequency or severity of the traumatic event, nor can it capture gender or cultural nuances.

**Conclusion**

A Mad Studies informed perspective was used in this paper to analyze chronic homelessness and to learn from lived experts to “re-imagine” a path to appropriate supports and services. We framed our analysis as a resistance to the medicalizing and pathology of homelessness as mental
illness. We acknowledge that there is tension in using survey data grounded in medical language in a study meant to challenge hegemony. However, we did not intend to present the data to substantiate arguments that homelessness is social disorder and disease. While we collected data in “traditional ways” our intention was to use the results to highlight long histories (sometimes intergenerational) of trauma, and to show how trauma has been reframed through psy and “expert” approaches as illness. The interventions that emerge from these approaches are assessment, scoring, ranking, diagnosis, and continued surveillance. For those with psychiatric histories and trauma, supports are inadequate as housing and support programs are not grounded in personal choice or healing.

Our results show that institutionalization of mad people continues, although in a different form, and that people have been made increasingly vulnerable due to failed public systems. The deleterious effects of former asylums, segregation, poor treatment, and ill health remains, though it is less visible. Chronic homelessness is the result of these failures and emergency shelters have become the modern day asylums. Solutions that are not inclusive of mad people’s voices could lead to a push for reinstitutionalization rather than an expansion of evidence-based practices for supporting people in trauma informed and dignified ways.

Solutions must be grounded in changes to policy that address systemic barriers which are forcing people to remain dependent through continuous institutionalization. Future research should be led by the voices of mad people through qualitative narrative examination of alternatives to current, mainstream, and dominant approaches. Future research should also apply a gendered approach to examine the experiences of women specifically, and how gender plays a role in people’s experiences. Further research is needed to understand the high rates of
Indigenous peoples in homeless shelters, their experiences of trauma and institutionalization and whether or not systemic racism and discriminatory practices are at play.

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