A qualitative, community-based exploration of self-care and mutual care among socioeconomically marginalized groups

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Thesis submitted to the University of Ottawa
in partial fulfillment of the requirements for the
Doctorate in Philosophy degree in Epidemiology and Public Health

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Preface

Lisa Boucher led all the scholarly tasks that contributed to this dissertation, including all literature reviews and conceptualization, study design, analysis and interpretation, and writing of the component articles as well as the introduction and discussion chapters for the dissertation. Drs. Kendall, Liddy, Leonard, Presseau and MacPherson provided expertise and insights at all stages of the dissertation process through regular meetings.

For Study 1, Lisa Boucher led the conceptualization, study design, analysis and interpretation, and writing of the two journal articles. Drs. Kendall, Liddy, Leonard, Presseau and MacPherson provided guidance throughout the study, as did the Community Advisory Committee members (Alana Martin, Dave Pineau, Christine Lalonde, Nic Diliso and Terry Lafleche). Drs. Shoemaker and Fitzgerald also supported conceptualization and analysis. Lisa Boucher wrote the complete first draft of the articles and all authors provided feedback prior to submission. The study was approved by Bruyère Research Institute (M16-19-027) and University of Ottawa (H-10-19-5175) Research Ethics Boards.

For Study 2, Lisa Boucher led conceptualization for the specific research question included in this dissertation, as well as leading the analysis, interpretation, and writing of the journal article. The broader study design process was co-led by Lisa Boucher, Zoë Dodd, and Dr. Young, with support from Drs. Bayoumi and Firestone. Dr. Kendall supported conceptualization of the research question and Abeera Shahid helped with analysis. Lisa Boucher wrote the complete first draft of the article and all authors provided feedback prior to submission. The Unity Health Toronto Research Ethics Board (#21-035) and the University of Ottawa Research Ethics Board (#H-03-21-6715) approved this study.

Abstract

Supports to improve self-care or self-management are beneficial for many people living with health issues, especially chronic conditions. Yet, socioeconomically marginalized groups have often been neglected from self-management initiatives, despite experiencing an increased prevalence of chronicity and multimorbidity. To this end, there are several established critiques within the self-management literature that are addressed through this dissertation. First, limited attention has been given to equity considerations within self-management, thus there remain gaps in the evidence base around disadvantaged groups. Second, there is a lack of understanding about the mechanisms that make self-management supports work, as well as little evidence to explain the wide extent of non-participation, including understanding the impact of structural barriers. Third, the social embeddedness of self-care has received little attention, despite people highlighting social roles as important concerns within self-care. In addition, the grassroots history of self-care has been neglected, which has resulted in minimal recognition of the role of mutual aid/self-help groups. This dissertation includes two exploratory, qualitative studies that attend to these knowledge gaps: the first explored self-care experiences among people who use drugs with chronic health issues, and the second explored mutual support among people experiencing homelessness within the context of encampments during the COVID-19 pandemic. The study findings are also contextualized by worsening overdose and housing crises. I employed community-based participatory research methods and the transformative framework to contend with social injustice and power imbalance and amplify the worldviews of marginalized groups. We conducted in-depth interviews and reflexive thematic analysis to analyze data. Overarching findings demonstrate the importance of agency in shaping how marginalized groups manage their health and social needs, the critical structural limitations they face in doing so, and the substantial influence of their formal and informal social supports. Thus, findings show the importance of recognizing these groups' alternative and holistic practices of care, the need to address structural and systemic barriers that inhibit their capacity for care, and the immense value of harnessing social support networks to meet care needs. Programs intended to support self-care among marginalized communities would benefit from incorporating a relational autonomy lens and community-centered approach.

Acknowledgements

I must acknowledge the many people who contributed to making my PhD possible. Foremost, I would like to express deep gratitude to my long-time mentor and doctoral supervisor, Dr. Claire Kendall. Claire is an exceptional researcher and important influence in my life, who has continually provided me with compassionate support, invested in and advocated for me, and offered much-needed perspective on all my endeavours. I also want to express immense gratitude to my other PhD supervisors, Drs. Clare Liddy and Lynne Leonard. Clare is a highly impressive researcher whose ongoing support, feedback and career advice has instilled great confidence in me. Lynne's expertise on qualitative inquiry has been critical to furthering my knowledge and I am truly a better researcher for it. I am incredibly lucky to be guided by so many strong women leaders. I also wish to sincerely thank my other thesis advisory committee members, Drs. Justin Presseau and Paul MacPherson, who have been extremely supportive and provided helpful guidance throughout my PhD studies.

I have also been so fortunate to have additional mentorship from several amazing colleagues at the Bruyère Research Institute. Namely, Drs. Esther Shoemaker and Michael Fitzgerald have been so generous in always being available as sounding boards and sharing valuable advice and positivity throughout my PhD. Further, I wish to thank two late colleagues, John Flynn and Lois Crowe, particularly for encouraging my pursuit of doctoral studies and reminding me to celebrate accomplishments along the way. You are both missed dearly.

I also wish to thank my remarkable community-based colleagues who inspired or contributed to this dissertation, most of whom I first worked with on the PROUD study (Participatory Research in Ottawa: Understanding Drugs). Many heartfelt thanks to Alana, Christine, Dave, Nic, Jenn, Sherri, Sean, and those who have passed on – RIP Brad, Rangi, and Terry. I doubt I would have pursued this doctoral trajectory if not for the life-changing insights gained from the PROUD team, as well as their friendships which have meant so much to me personally. I am always inspired by the resilience, kindness, and passion of the community members with whom I collaborate.

I also want to express much gratitude to the participants in my PhD studies for sharing so much of their stories, as well as the fantastic community organizations and groups who supported this work. I hope this research honours the lives of the many marginalized community members who have tragically died in our setting due to the overdose crisis and lack of access to adequate supports. There has been no greater motivation to persist in this PhD than my desire to address the extreme injustices inflicted on marginalized communities.

I would also like to thank my Toronto colleagues, especially my incredible co-leads on the encampments sub-study, Dr. Samantha Young and Zoë Dodd. While Zoë's unwavering advocacy has been an inspiration since long before I got the opportunity to work with her, her substantial insights have also contributed greatly to my broader thinking for this dissertation. I also wish to acknowledge the helpful support of the larger MARCO study, especially from the principal investigators, Drs. Ahmed Bayoumi and Michelle Firestone. Further, I want to thank several MARCO colleagues who are new leaders in their respective fields, Drs. Gillian Kolla and Alexa Yakubovich, with whom I am grateful to have had the opportunity to collaborate.

Finally, I would not have made it through all the challenges of this PhD without my wonderful husband, Colin, who has been my primary source of support and my constant source of energy, comfort, and joy. I will also always be super grateful for my amazing parents, Mary and Steve, and my brother, Jon, whose love and support has shaped all my life pursuits. Further, I am very grateful to have highly supportive in-laws and friends. Though my family and friends may not understand my research or why my studies have taken so long, they are truly the most caring people imaginable, which has made all the difference in keeping me going through the struggles of this doctoral journey.

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Chapter 1: Introduction

1.1 Background

Complexity abounds in caring for socioeconomically marginalized groups, including people who use drugs (PWUD) and people experiencing homelessness. These groups tend to experience heightened morbidity, including health conditions characterized by chronicity and multimorbidity, as well as stigmatization and disparities in the social determinants of health (Degenhardt et al., 2013; Guirguis-Younger, McNeil, & Hwang, 2014; Kreek, 2011; Public Health Agency of Canada, 2018). PWUD have 15 to 20 years lower life expectancy than the general population (Degenhardt et al., 2013), while people experiencing homelessness have approximately 3-4 times the mortality rate of the general population (Henwood, Byrne, & Scriber, 2015), including one of the highest mortality rates in Canada (Guirguis-Younger et al., 2014). However, these groups are often not considered within initiatives designed to address chronic health conditions, such as self-management supports. Lack of attention to equity considerations may be perpetuating a gap in provision of self-management services for these marginalized groups. Considering the complex health and social issues they face, including urgent crisis-related issues that likely reduce capacity for self-managing longer-term issues, the need to deliver such services may be substantial. In this introduction, I will describe the literature on the topic of self-management among socioeconomically marginalized groups. Insights from multiple fields, but especially sociology, were drawn upon to contextualize and critically examine the current evidence base in this important area of public health.

1.1.1 Self-management as a key element of chronic illness care

Within Canada, self-management is often framed through the Expanded Chronic Care Model (Barr et al., 2003), which has been recommended and adopted for the prevention and management of the increasing prevalence of chronic disease (Ontario Ministry of Health and Long-Term Care, 2007). A key domain of the Expanded Chronic Care Model pertains to self-management and developing personal skills (Barr et al., 2003). Self-management in this context may be defined as relating to “the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with the medical management, role management and emotional management of their conditions" (Adams, Greiner, & Corrigan, 2004). Recognizing that patients, especially those living with chronic conditions, practice self-management day-to-day outside of the healthcare arena, self-management support aims to help increase their confidence, motivation, knowledge, and skills to cope well with the impacts of their illness (Liddy, Blazkho, & Mill, 2014; Lorig, 2002). Self-management support may be an objective of many types of services, ranging from visits with health or social care providers, to patient navigation, to health coaching, to explicitly-named self-management programs, to self-help/mutual aid groups. Still, self-management initiatives have been differentiated from traditional health education by an emphasis on skill-building activities (e.g., problem solving, decision making, finding and utilizing resources, forming partnerships with providers, and taking action) as well as self-tailoring the principles of behaviour change to one's own circumstances (Lorig, 2002; Lorig & Holman, 2003). Self-management interventions are typically considered health behaviour change interventions, and given their multiple interconnecting components, they tend to be complex interventions (Campbell et al., 2000; Craig et al., 2013).

A critical element of many self-management initiatives is the involvement of people with lived experience in design or delivery. In fact, many popular programs were developed by people who have health conditions themselves, including the Chronic Disease Self-Management Program (CDSMP) and Wellness Recovery Action Planning (WRAP) (Davidson, 2005). Individuals with lived experience (often termed "peers") also typically play a key role in the provision of self-management programs (e.g., as facilitators or mentors). The peer-to-peer support they provide, as well as that occurring among the participants in group programs, is generally considered an important mechanism contributing to the success of these programs (Advocates for Human Potential, 2022; Lorig & Holman, 2003). Other formalized peer support initiatives may also enhance self-management, regardless of whether self-management is an explicit goal of such initiatives, and peer support may further facilitate self-management through its natural occurrence in communities. Similarly, many other existing health and social services or community resources may result in helping people to self-manage without express intentions to do so.

Self-management is defined in a variety of ways based on different perspectives or contexts, with application of the concept often lacking coherence or consistency in the literature. For instance, there has been confusion across the three terms “self-managing”, “coping”, and “adapting”, with a concept analysis finding that these activities are different yet overlapping, and may be best understood as forming a “complex whole” that represents people’s experiences of living with chronic conditions (Audulv, Packer, Hutchinson, Roger, & Kephart, 2016). Further, a concept and dimensional analysis of “self-management” found that the literature predominantly reflects healthcare professional perspectives (e.g., emphasizing adherence to a plan), with patient perspectives requiring further research (Udlis, 2011). Another concept analysis distinguished “self-management” from both “self-care” and “self-management support”, finding that self-management typically involved coping with or controlling illness rather than maintaining health (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011). Yet, in wider understanding and practice, the terms “self-management” and “self-care” tend to be used interchangeably, thus I will use them interchangeably in this dissertation. Self-care activities are essential to the human experience; thus they extend beyond the health/illness experience (whether for disease management or prevention), with some degree of self-care necessary simply to meet basic survival needs. For instance, some have defined the overall concept quite generically, including the following: “Self-management is something we all do. It is whatever we do to make the most of our lives by coping with our difficulties and making the most of what we have...” (Martyn, 2002). Self-care has also been considered interrelated with caring for others, as this broad definition suggests:

> ...a range of care activities deliberately engaged throughout life to promote physical, mental and emotional health, maintain life and prevent disease. Self-care is performed by the individual on their own behalf, for their families, or communities, and includes care by others. In the event of injury, disability or disease, the individual continues to

> engage in self-care, either on their own or in collaboration with healthcare professionals. (Godfrey et al., 2011)

1.1.2 History of self-management/self-care and mutual aid/self-help groups

The long history of self-management can be traced to Graeco-Roman times, through mutual aid traditions such as the Friendly Societies and Unions in early modern Europe, gaining importance due to the chaotic social effects of the Industrial Revolution, and transforming into the self-help and self-care movements of the twentieth century (Katz, 1981; Katz & Bender, 1976; Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011; Newbould, Taylor, & Bury, 2006). Evidence of natural support systems has existed since the earliest historical records, with cooperation possibly being the most important contributor to continuing human existence (Katz & Bender, 1976; Kropotkin, 1902). Several decades ago, Katz and Bender (1976) described the contemporary organization of mutual aid as including both: 1) informal or naturally-occurring social networks of kith and kin, and 2) socially supportive, self-organized and self-directed groups. They highlighted that the latter – termed "self-help groups" – had experienced a proliferation in recent decades due to social changes after World War II. These groups were formed among people with some type of common goal or experiencing a similar health or social disadvantage, thus providing support for each other's learning, healing, and action. Self-help groups typically provided material and psychosocial support (e.g., services and emotional support), while meeting people's needs for affiliation and identity. Thus, they served both instrumental and expressive functions, which distinguished them from other types of voluntary groups (Katz, 1981). Further, many groups were formed to manage "deviance" from normative behaviours, which was generally approached in one of two ways: reforming the individual members or reforming society at large. Some scholars even classified certain self-help groups as "social movements" to reflect their function of social change, including through solidarity amongst stigmatized or disenfranchised groups (Katz, 1981; Katz & Bender, 1976).

Self-help groups have been highly diverse in both purpose and process (Katz, 1981). A large proportion of early self-help groups were dedicated to health-related issues, such as those formed by patients with a particular (often complex or rare) health condition who had not found support or success within the dominant medical system. In addition, self-help groups were common among people traditionally considered socially deviant (e.g., PWUD), who often also experienced socioeconomic struggles:

> Self-help forms and practices are found in a variety of organizations that promote self-care in physical and mental health for self or relatives, in housing cooperatives and other economic projects, in groups set up to help so-called "deviants" (e.g. homosexuals, ex-convicts, ex-prostitutes, and former mental patients) reclaim or redefine their position among humanity... (Katz, 1981)

Historical records also specifically highlight the prominence of mutual support among people living in poverty: “Every kind of witness in the first half of the 19th century...remarked upon the extent of mutual aid in the poorest districts” (Katz & Bender, 1976; Thompson, 1963). There is also a long history of mutual aid in the addiction field, as many of the earliest empirical social science studies on self-help groups centered on Alcoholics Anonymous (Katz, 1981), the widespread network of abstinence-based, peer-led support groups for people with alcohol or drug use issues, which developed the spiritually-oriented “Twelve Step program”.

While self-management/self-care and self-help/mutual aid traditions are historically intertwined, they were rediscovered and diverged in recent decades (Katz & Bender, 1976; Kendall et al., 2011), and can be considered “coeval aspects of the same general phenomenon” (Katz, 1981). Around the same time as the movement and literature on self-help groups began to proliferate, medical self-care emerged with its own movement and body of literature, sharing features of self-help but with the core distinction that it could be practiced alone or within a small unit (e.g., the family) (Katz, 1981). While self-care is broader in this sense, it is also narrower in that it primarily applies to how people manage their health, and, more often, specifically their illness.

In addition, both self-help and self-care are intertwined with the growth of medical consumerism since the 1960s (Iliffe & Manthorpe, 2020; Kendall et al., 2011), which has evolved through three generations of conceptualization, though its original intent was the “patient challenge to physician authority” in response to paternalistic medical systems (Iliffe &

Manthorpe, 2020). The first generation resulted in a proliferation of self-help organizations, while the third and most recent generation (beginning in the 1990s) emphasizes "successful aging" and individuals who are fully engaged in self-managing their health.

Though early champions of self-management were from the voluntary sector, the past few decades have seen self-management embraced by policymakers as an important means to curb inefficient use of healthcare resources and reduce costs related to the increase in chronic conditions (Rogers, 2009). Governments have also cited the promotion of self-management as a way to improve quantity and quality of life as well as reduce health inequities. Yet, despite incorporation into official health policies, "both the radical/oppositional and collective aspects of bottom up patient action" that were foundational to self-management history have been left out of the discourse, which may neglect aspects that are important to laypeople (Rogers, 2009), especially marginalized groups. This is perhaps not surprising given that notions of informal care only entered policy agendas in the late 1990s.

Moreover, while the term "self-care" may have originated in medicine, its infiltration into wider society likely has more radical roots. For instance, some scholars have recognized members of the Black Panther Party as spreading the importance of self-care, both through their acts of community care and as a way for activists to maintain their own well-being while engaging in political resistance (Davis, 2018). There is a famous quote from the influential Black feminist writer Audre Lorde, that reads: "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare" (1988). Relatedly, self-care has been long recognized as critical for professional care providers as well as unpaid family or friend caregivers to enhance their ability to care for others. In addition, these experiences align with longstanding perspectives on the centrality of the relationship between self-care and mutual care, which may be conceptualized as 'two sides of the same coin':

> In the life of the individual, as well as in the life of groups, self-help and help from others are equivalent features. They reflect basic aspects of the human situation. The one begins where the other ends or fails. Seen in human life as a whole, self-help and help from others are not contrasts but complements. (deJongh, 1954)

On the whole, references to self-management/self-care have become increasingly common across academia, healthcare and public health practice, and among the broader public. For example, the term “self-management” saw a 74% increase in use since 2015 among articles focused on HIV in low- and middle-income countries (Davis et al., 2022). Self-care has often been called a “buzzword” in the media. However, in recent discourse, some marginalized groups have emphasized the need for a more holistic and relational approach to self-care, claiming that it has been co-opted within neoliberal approaches. These groups may prefer to use the term “community care” or at least to qualify the term by saying “collective self-care” or “radical self-care”, in attempts to recapture the grassroots community action that is central to self-care history (Hobart & Kneese, 2020; Michaeli, 2017). Sociological literature also suggests that people’s actual chronic illness management experiences conform less to ideas of *self*-care and more to “household/social network/community care management” (Tausig, 2013).

1.1.3 The Chronic Disease Self-Management Program

The Chronic Disease Self-Management Program (CDSMP), offered by the Self-Management Resource Center (Self-Management Resource Center, 2018), is likely the most widely available and recognized self-management program, adopted across much of North America and the United Kingdom (Johnston, Liddy, Mill, & Irving, 2012; Kennedy, Reeves, et al., 2007; Ory et al., 2013). In the Canadian context, most provinces offer the CDSMP as public health programming, and several offer disease-specific variants as well. The program is based on principles of social cognitive theory, especially perceived self-efficacy (Bandura, 1977, 1986; Lorig, 2015), and involves 2.5 hour group sessions once a week for six weeks (Self-Management Resource Center, 2018). The program is designed to be led by peers (i.e., in this case, people with lived experience of a chronic condition) (Self-Management Resource Center, 2018), although in practice it is sometimes co-led with a professional health care provider. Participants in the program mostly have commonly occurring conditions (e.g., diabetes, asthma, chronic obstructive pulmonary disease, arthritis, or cancer), and, notably, they usually have more than one chronic condition (Ory, Ahn, Jiang, & Smith, 2013). The program has well-established effectiveness for improving health behaviours, health outcomes, health care and quality of life, and reducing health care utilization and costs (Ahn et al., 2013; Allegrante, Wells, & Peterson, 2018; Brady et al., 2011; Ory et al., 2013).

There are some studies of the CDSMP with complex populations, including ethnic minorities (Griffiths et al., 2005), vulnerable older persons in frail health (Jonker, Comijs, Knipscheer, & Deeg, 2015), and frequent health care users (Hudon et al., 2016). Moreover, of relevance to marginalized groups, there have been several CDSMP studies focused on populations with serious mental illness, with most showing acceptability or positive effects (Druss et al., 2010; Goldberg et al., 2013; Lawn et al., 2007; Lorig, Ritter, et al., 2014; mhca Care Management Bulletin, 2015). Ritter et al. (Ritter, Ory, Laurent, & Lorig, 2014) also compared secondary data for CDSMP participants with and without depression and found similar benefits among both groups.

As well, specific populations have been studied using disease-specific versions or adaptations of the CDSMP, including with people living with HIV (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998; Kennedy, Rogers, & Crossley, 2007; Sullivan & Inouye, 2015; Webel, 2010), hepatitis C (Groessl et al., 2013), and for managing stroke or diabetes risks among minority ethnicities, such as Black and Latino individuals (Goldfinger et al., 2012), a low income, uninsured, Spanish-speaking population (Horowitz, Eckhardt, Talavera, Goytia, & Lorig, 2011), and American Indians and Alaska Natives (Jernigan & Lorig, 2011). The mostly positive results from these studies also point to potential for the use of the generic version among similar groups, since the core principles and skill-building activities are consistent across all versions (Lorig, Laurent, Plant, Krishnan, & Ritter, 2014). In fact, several studies have compared generic and disease-specific versions and found similar effects between programs (Ghahari, Packer, Boldy, Melling, & Parsons, 2015; McGowan, 2015).

However, it is notable that many of the CDSMP (or disease-specific variant) studies that aimed to expand to groups who are underserved or experiencing mental health issues used participatory approaches and modified versions of the program (Jernigan & Lorig, 2011; Druss et al., 2010; Goldberg et al., 2013; Goldfinger et al., 2012; Horowitz et al., 2011; Lawn et al., 2007). Further, results of qualitative studies of these programs have found that homogenous groups of participants were considered more appropriate because they facilitate connectedness and cultural acceptability (Jernigan & Lorig, 2011; Hudon et al., 2016), thus this implementation approach may be especially important for people experiencing stigma who often rely on peer support.

1.1.4 Self-management supports are diverse and multifaceted

Many other initiatives include self-management as a primary objective, or as one among multiple other goals. Within the mental health field, Wellness Recovery Action Planning (WRAP) is likely the most common initiative that explicitly takes a self-management approach (Scott & Wilson, 2011). On the whole, WRAP follows a similar structure as the CDSMP, yet it also incorporates a "recovery" approach which may be more valuable for addressing mental health problems (Davidson, 2005). WRAP was originally developed in 1997 by mental health consumers (i.e., patient, client or service user) intending to support each other in filling the gaps left by mental health professionals with respect to daily management of their conditions. The process involves creating a thorough management plan for identifying one's risks (or "triggers") and ways to intervene early to restore well-being. It follows several core values, including self-determination, equality, mutual learning, simplicity and safety, being a way of life, hope, and a non-political stance. It is delivered via a self-help group model with two formally trained peers who teach material and facilitate discussions over the course of several hours per week for 8 weeks (Advocates for Human Potential, 2022). WRAP has been widely applied in multiple countries and across many types and severity of mental health conditions (and sometimes other health, personal, or life course issues). While it was designed and has evidence to support the program being fully directed by consumers, in being taken up by public health and community services it has sometimes been taught by non-consumers (Advocates for Human Potential, 2022; Scott & Wilson, 2011).

Patient navigation or health navigation is another initiative which cites building capacity for self-management as one of multiple goals (Broeckaert, 2018). First developed in 1990 to support low-income patients with cancer to navigate complex health services (Wells et al., 2008), these initiatives have now been adopted for many other patient populations (McBrien et al., 2018). Patient navigator programs often involve helping people overcome both health system and patient-related barriers, as well as providing health education and psychosocial support. Peer navigation is a specialized form of this model, employing laypeople with some type of shared lived experience to the patients they are meant to help (Sheehan et al., 2017). Not surprisingly, this variation of the model has become prominent among marginalized communities, which typically embrace the ‘nothing about us without us’ mantra. For instance, in the HIV field, extensive practice guidelines have been developed to support the engagement of people living with HIV in health navigator roles (Broeckaert, 2018). Meta-synthesized qualitative evidence demonstrated that patient navigation programs were highly beneficial for people living with HIV, including due to the holistic approach of the navigation and the strong relationships patients formed with the navigators (Roland et al., 2020). Similarly, this approach has been used in the harm reduction field to support PWUD (CATIE, 2022), as well as in other settings to support multiply marginalized groups, such as people experiencing homelessness or unstable housing who are codiagnosed with HIV and substance use or mental health conditions (Sarango, de Groot, Hirschi, Umeh, & Rajabiun, 2017), and African Americans experiencing homelessness and serious mental illness (Corrigan et al., 2017).

1.1.5 Critiques of current self-management programs and literature

Recently, an international group of self-care researchers summarized many behaviour change and illness-related factors that present challenges in the field, and outlined the following six knowledge gaps that should be investigated further to address these:

> …the influence of habit formation on behavior change, resilience in the face of stressful life events that interfere with self-care, the influence of culture on self-care behavioral choices, the difficulty performing self-care with multiple chronic conditions, self-care in persons with severe mental illness, and the influence of others (care partners, family, peer supporters, and healthcare professionals) on self-care. (Riegel et al., 2021)

This group also provided eight methodological recommendations for how to grow the evidence base on self-care (Jaarsma et al., 2020). Their final recommendation pertains to the need to improve measurement practices in self-care research and evaluation, such as including variables that influence self-care on both individual and societal levels. For instance, some variables they mention that are relevant to the marginalized communities included in the studies within this dissertation are social support, multimorbidity, and access to resources and care.

Further, other international expert consensus has focused on how self-management initiatives pay insufficient attention to disadvantaged populations, identifying health equity as a priority for advancing the field (Mills, Brady, Jayanthan, Ziabakhsh, & Sargious, 2016). Their International Framework for Chronic Condition Self-Management Support highlights seven strategic directions, including the need to meaningfully engage people with lived experience in self-management initiatives, expand the reach, range and access of self-management supports, and improve the evidence base with respect to appropriateness and effectiveness of interventions (Mills et al., 2016). These equity-enhancing actions will be imperative to ensure the relevance of supports among (socioeconomically) marginalized communities.

Ultimately, it is clear that the current evidence base for self-management contains many gaps. To provide context for my studies, I will describe three well-documented critiques of the literature base that are addressed by the two original studies in this dissertation. For instance, this dissertation will provide insights into self-care with respect to reducing barriers that perpetuate health and social inequities, contributing to understanding mechanisms, and highlighting the influence of social support. Other specific topics I explore which were highlighted as knowledge gaps include the influence of culture or stressful life events on self-care, as well as the influence of self-managing with multiple chronic conditions or severe mental illness (Riegel et al., 2021).

1.1.5.1 Gaps among disadvantaged groups

Many critiques in the self-management literature centre on the gaps that exist with respect to disadvantaged groups. Scholars have highlighted the need to reduce barriers and tailor self-management initiatives for disadvantaged groups to avoid increasing health inequities (Kendall et al., 2011; Mills, Bergeron, & Pérez, 2015; Packer et al., 2012; Rogers, 2009), including through expanding programs across spectrums of ethnic diversity and health literacy (MacKey, Doody, Werner, & Fullen, 2016; Sarkar, Fisher, & Schillinger, 2006). For instance, Kendall et al. (2011) have detailed the ways current self-management discourse includes multiple assumptions that may impinge on equity, such as emphasizing individual rather than collective responsibility for self-management, privileging professional or dominant ways of knowing over people's own experiential or cultural knowledge, and assuming that the freedom to 'choose' while self-managing is available to everyone. They also argue that this is related to the medicalization and appropriation of self-management by health systems, so that it more closely reflects the traditional beliefs and goals of these systems (which often prioritize cost-saving) rather than the goals and beliefs of people living with health issues (Kendall et al., 2011). They suggest that the term "self-management" has been overused and misunderstood, resulting in relatively rare reflection on its meaning for patients.

There also appears to be limited access or interest in self-management programs among certain individuals, represented by evidence that a low percentage of people who are referred to such programs actually participate, and among those who do, completion rates are low (Iliffe & Manthorpe, 2020; Rogers, 2009). There is a lack of formal assessment for the reasons that people drop out or choose not to engage in self-management programs (Trappenburg et al., 2013), which may obscure the inadequate attention to equity considerations. One systematic review found that patients were less likely to enroll or complete a program if they had: limited disease-specific knowledge, negative outcome expectancies of self-management, confusion about comorbidity self-care, scheduling conflicts, or believed their current health care was sufficient; whereas they were more likely to participate if they desired or received strong social support from providers or facilitators (Paige, Stellefson, & Singh, 2016). This review also found limited reporting of evidence for the impact of demographic and sociostructural factors, with lower participation associated with low income in two of 13 studies and with older age and job commitments in one study.

With the CDSMP specifically, some have noted that participants self-select into the program (including in randomized trials), which has resulted in samples that are mostly white, English-speaking women, who are insured and have higher education and income levels (Lindsay & Vrijhoef, 2009; Newbould et al., 2006). The CDSMP also typically has 15 to 20% attrition (Verevkina, Shi, Fuentes-Caceres, & Scanlon, 2014). In one study, low baseline self-efficacy for managing chronic disease, younger age, and lower education compared to other group members were all associated with attrition (Verevkina et al., 2014). Shi et al. (2017) found that a greater number of chronic conditions was associated with program completion, as was smaller class size, and African American ethnicity. Hudon et al. (2016) assessed non-participation and non-completion specifically among a vulnerable group of frequent health care users, finding that 36% agreed to participate and 47% of those completed the program. They found participants with greater anxiety or depression were more likely to participate. Reasons for non-participation included group format or logistics (i.e., time or transportation), whereas improvement in disease condition or bad weather led to no-shows among those who had expressed interest. Reasons for attrition included heterogeneity among group members (in regard to “different levels of vulnerability”, severity of disease, age, or different chronic diseases) as well as poor health. Implementation factors – such as group composition, experience level of facilitators, abstractness of content, location, and schedule – were also important to program success.

Overall, research on supporting self-management among people with complex chronic diseases is scarce (Sevick et al., 2007). There is evidence that the CDSMP “perpetuates the medical model and fails to reach those most in need” (Lindsay & Vrijhoef, 2009) while also giving inadequate attention to multimorbidity (Lindsay & Vrijhoef, 2009; Silver, 2018). Multimorbidity denotes the presence of multiple co-occurring chronic health conditions in an individual, and is increasingly important as the prevalence of people living with two or more conditions is growing globally (Nicholson et al., 2019). Multimorbidity also relates to increasing complexity in addressing people’s health and social needs, with these trends suggesting the value of person-centered care approaches rather than disease-oriented approaches (Koné Pefoyo et al., 2015). Despite having greater multimorbidity and worse outcomes, socioeconomically disadvantaged populations have less access to and greater attrition from self-management programs (Lindsay & Vrijhoef, 2009; Mills et al., 2014). Still, among those who do participate, studies have shown positive results (Mills et al., 2014).

1.1.5.2 Limited understanding of intervention effectiveness

Another critique within the literature pertains to the lack of high-quality evidence supporting self-management programs, with studies finding mainly modest or equivocal effects (Lindsay & Vrijhoef, 2009; Newbould et al., 2006; Nolte, Elsworth, Newman, & Osborne, 2013; Rogers, 2009). There have been many calls to increase evaluation capacity to improve the evidence base for self-management support (Jaarsma et al., 2020; Johnston et al., 2012; Mills et al., 2016; Trappenburg et al., 2013). As self-management programs typically constitute complex interventions, evaluations should incorporate an assessment of process factors, including implementation, mechanisms, and context, as well as outcome evaluations that include multiple types of outcome measures and patient-reported outcome measures (Craig et al., 2013; Engler, Lessard, & Lebouché, 2017; Moore et al., 2015; Nolte et al., 2013). As noted above with respect to reducing inequities, building the evidence base should also include a better understanding of contextual and implementation factors relevant to enrollment and attrition (Mills et al., 2014). In addition, the processes of change involved in making self-management interventions successful are poorly understood, suggesting a need for careful delineation of causal pathways as well as high-quality mixed methods evaluations (Jaarsma et al., 2020; Muralidharan, Peeples, & Lucksted, 2021).

Improved investigation into the role of peer support in self-management interventions is also needed. Some evidence suggests that peer versus professional support in self-management programs may not affect outcomes (Lindsay & Vrijhoef, 2009; Rogers, 2009), yet peer support tends to be highly valued among marginalized groups who are unlikely to be captured in such data. Also, existing evidence has not adequately separated the effects of peer support from effects specific to other components of self-management interventions. Such differential effects may be better understood through the use of more appropriate study designs, such as a factorial design which allows testing different components at the same time (Jaarsma et al., 2020). Similarly, although many different types of initiatives may contribute to enhancing self-management, much literature referring to self-management support is unclear about which type or component(s) of self-management is involved, while other relevant literature does not use the terms “self-management” or “self-care” at all and thus remains uncaptured within the evidence base. For example, self-management *skill-building* programs are sometimes conflated with other health education initiatives that mainly contribute to self-management *knowledge*, thus presenting challenges for identifying overarching causal mechanisms. These issues may be resolved through improved reporting of intervention component details and thoughtful eligibility criteria in knowledge syntheses (e.g., systematic reviews). Notably, the peer support field shares a similar lack of high-quality evidence, likely also related to measurement challenges that plague such complex interventions. As Watson (2017) argues, the outcomes investigated and thus the evidence produced has not reflected the meaning and nature of peer support itself. As outcome measurement is also an area of concern in the self-management literature (Jaarsma et al., 2020; Nolte et al., 2013), outcome selection needs to better reflect the complex nature of self-management interventions as well as patient preferences (e.g., prioritizing patient-reported outcome measures).

1.1.5.3 Lack of attention to social embeddedness

There is also growing emphasis on the need to recognize the social elements of self-management (e.g., social networks and social capital), especially with attention to socially or economically marginalized groups (Goodridge et al., 2019; Morris, Kennedy, & Sanders, 2016; Rogers et al., 2011; Tausig, 2013; Vassilev et al., 2013, 2011). Many researchers have critiqued the focus on changing individual health behaviours in current self-management initiatives (Kendall et al., 2011; Lindsay & Vrijhoef, 2009; Rogers, 2009), highlighting how these approaches demonstrate limited understanding of the ways that self-management is socially embedded, including the effects of both positive and negative aspects of social contexts. For instance, people living with HIV have highlighted social support as an important aspect of self-management programs (Bernardin, Toews, Restall, & Vuongphan, 2013; Embuldeniya et al., 2013; Roth et al., 2012), yet participating in social activities and roles has been a neglected outcome in self-management research (Packer et al., 2018).

In general, social support has a well-established influence on people's health and well-being (Hogan, Linden, & Najarian, 2002). Social support networks are also vital to self-management (Vassilev et al., 2011), with a qualitative metasynthesis highlighting several mechanisms for such effects, including the degree of network navigation, negotiation within networks, and collective efficacy (Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014). People's social support systems can include both informal and formal supports, including family, friends, neighbours, community groups, peers, and professional care providers. People experiencing illness typically receive most of their support from informal or unpaid caregivers, most commonly their spouses or adult children (Vassilev et al., 2013). People also experience differing degrees of social or community integration, which greatly impacts the resources they may draw on for self-management (Berkman, Glass, Brissette, & Seeman, 2000).

Similarly, with respect to broader environmental and social contexts, some authors have critiqued self-management discourse for limited understanding and acknowledgement of the extensive "illness work" that patients engage in within their daily lives and communities (outside of formal health systems), which represents the vast majority of people's experiences with chronic illness (Kendall et al., 2011; Newbould et al., 2006; Rogers, 2009). Even more so, self-management discourse neglects the "everyday-life work" (domestic tasks, employment) and "biographical work" (reconstruction of identity) that people continually engage in to adapt to living with their illness, and which they may prioritize over symptom-focused illness work (Corbin & Strauss, 1985; Rogers, 2009). This disregard is demonstrated by the way self-management messaging within health systems is often framed as suggesting that people need to be taught how to become experts on self-care, which neglects to recognize the expertise people already have on their own self-care. This is not to say that people with health issues do not require self-care support, however, as their self-care work is often challenging, time-consuming, and changing throughout the lifespan. Thus, re-framing self-care initiatives as meant to simply support people's extensive work has been promoted as an alternative orientation to better honour the value of their experiential knowledge (Rogers, 2009).

On the whole, it is likely that limited attention to social embeddedness relates to the individualization and medicalization of self-management, which has often resulted in expectations that people with illness are responsible for adhering to normative health behaviours, with failure to do so resulting in 'victim-blaming' (Iliffe & Manthorpe, 2020; Kendall et al., 2011; Lindsay & Vrijhoef, 2009). Further, self-management discourse indicates that people are simultaneously disenfranchised *and* held responsible – in that they are considered to need instruction from healthcare professionals, but if they cannot or do not follow it (or it does not work for them) then they are deemed at fault for their problems (Kendall et al., 2011). Scholars have delineated a critical tension with respect to the community origins of self-care support – that is, "consumer action struggling against the grain of a paternalistic and condescending mainstream health system" (Scott & Wilson, 2011) – and the directions these initiatives have taken as they have been increasingly promoted within health systems (Iliffe & Manthorpe, 2020; Scott & Wilson, 2011). Relatedly, the individualization of self-management has spurred marketization and commodification, resulting in a growing self-care industry while community-focused and social welfare initiatives have been neglected (The Care Collective, 2020).

Similar issues have been identified among formal peer support initiatives. Watson (2017) explains that this is partly because the research has focused on peer support within mainstream health systems that are based on the medical paradigm and follow a positivist orientation, which reflects a philosophical orientation that is not necessarily conducive to the principles of mutuality, power sharing, and trusting relationships at the root of peer support. Watson (2017) further notes that some people have expressed uncertainty about whether peer support can exist in such mainstream spaces (as they are currently structured) without being co-opted and far removed from its mutual support roots. Thus, Watson (2017) recommends that peer support be located within communities and embrace mutuality, focusing more on collective versus individual issues, while acknowledging inequities and avoiding the de-politicization that occurs through removing experiences from their context. These recommendations may also be essential for improving self-care supports among marginalized groups. Accordingly, a few qualitative evaluations of self-management programs with groups experiencing varying degrees of marginalization found that participants valued mutual support among their fellow participants more than other aspects of the programs (and especially among those who shared the most similar experiences), including the act of providing support to one's peers (Kennedy & Rogers, 2009; Kennedy, Rogers, et al., 2007). Hence, current structures of having peers employed as leaders of programs may inadvertently place them in a hierarchical position to the peers they are intended to support, potentially limiting the effectiveness of such supports. This overall sentiment was a main conclusion stemming from the evaluation of experiences of people living with HIV who participated in the Positive Self-Management Program (PSMP; i.e., a disease-specific version of the CDSMP):

> In terms of implications for practice, it is clear that despite the focus of the PSMP on increasing self-efficacy, making individual behavioral change and the emphasis on increasing personal responsibility; the generation of features more associated with self-help groups and mutual support (discussed in the introduction) are as important as the process and outcome of such groups, if not more so. (Kennedy, Rogers, et al., 2007)

Inattention to social factors are similar to the gaps identified among other health promotion strategies that centre on behaviour change, which have been accused of neglecting social determinants of health and thus inadequately addressing (or even exacerbating) existing inequities (Baum & Fisher, 2014; Montiel, Radziszewski, Prilleltensky, & Houle, 2021). Given that a larger proportion of health outcomes is often attributable to social determinants than to individual lifestyle factors (World Health Organization, 2022), more attention to how social determinants affect self-management is warranted. Furthermore, the individualistic, health-focused approach of many self-management programs is unlikely to be appropriate for all cultural traditions nor all social circumstances, and neglects that patients may have more pressing needs than self-managing health issues (Kennedy & Rogers, 2009; Riegel et al., 2021). In response to the long-time policy concern of social determinants of health, a Commission by the World Health Organization declared that “social injustice is killing people on a grand scale” (2008) and provided recommendations focused on upstream interventions, such as increasing regulations and altering environments, rather than increasingly focusing on individual lifestyle changes. However, the emphasis on personal responsibility in such approaches is attractive for governments and health systems that hope to contain costs in the context of aging populations and increasing chronic illness (Baum & Fisher, 2014). Broadly, the predominance of individual risk- or behaviour-based initiatives in healthcare and public health will likely do little to reduce health inequities without simultaneous investment in addressing the sociostructural root causes of such inequities (Baum & Fisher, 2014). Given the burden of illness concentrated among marginalized groups, greater attention to the causes of inequities within self-management supports is an ethical imperative.

Some scholars have expressed expectations that the use of holistic models that consider people’s social and political contexts may improve the self-management field (Lindsay & Vrijhoef, 2009; Silver, 2018). Many self-management initiatives to date have been explicitly apolitical, which may not serve marginalized individuals who are often negatively affected by policy decisions. Further, an emphasis on more relational approaches may contribute to reconciling self-care and mutual aid traditions, insofar as the focus on self-care as an individual practice has de-emphasized the importance of mutuality within people’s natural self-care.

1.1.6 Socioeconomic marginalization and self-management

Marginalization has been defined in numerous ways, though in general the term refers to a process by which people are considered different from the norm and thus “peripheralized on the basis of their identities, associations, experiences, and environments” (Hall, Stevens, & Meleis, 1994). Marginalization often involves oppression, alienation, stigmatization or segregation, though these are distinct concepts. Ultimately, it involves some form of systematic exclusion from meaningfully participating in wider societal activities (e.g., social, economic, cultural, political), though it is most closely associated with lack of material resources because it commonly affects groups who experience poverty, including people with disabilities (which includes many PWUD experiencing multimorbidity), visible minorities, the unemployed, and people experiencing homelessness (Jenson, 2000). Marginalization is also sometimes used specifically to refer to unique experiences of particular groups (e.g., marginalized due to race or gender).

In this dissertation, I employ a conceptualization specific to *socioeconomic* marginalization with the intent to focus on the social exclusion that occurs when people experience financial struggles to the point that their participation in the dominant system of labour is disrupted. Hence, the condition of being socioeconomically marginalized is more than simply having low income – it involves facing class-based exclusion. Such exclusion is often a product of discrimination that tends to centre on certain groups who are considered “undeserving” of support (Dej, 2020). Further, many socioeconomically marginalized people also identify with other marginalized groups, thus facing intersectional stigmatization (e.g., racism, sexism, homophobia, transphobia, ableism).

Marginalization is interconnected with the social determinants of health, such that people experiencing marginalization are more likely to experience negative social determinants of health. The social determinants of health are defined as “the circumstances in which people are born, live, work and age, and the systems put in place to deal with illness” (Solar & Irwin, 2010). Marginalization and the social determinants of health both tend to cluster among people in disadvantaged social positions (e.g., poor, racialized, LGBTQ2S+), and are also exacerbated by the combination of multiple disadvantaged positions (Baah, Teitelman, & Riegel, 2019). This means that unhealthy environments and behaviours, and thus negative health outcomes, are more common among socioeconomically marginalized groups, with health disparities increasing along a social gradient (Baum & Fisher, 2014). Further, many adults living in poverty were once children living in poverty and self-management is shaped by experiences over the life course, with childhood deprivation affecting health behaviours and outcomes in later life (Lindsay, 2009). These early experiences interfere with the ability to develop coping skills and later engage in health-promoting behaviours, as such behaviours require resources which socioeconomically marginalized populations often lack (Lindsay, 2009). Thus, socioeconomically marginalized adults tend to have accumulated greater chronic health issues over time and likely have greater needs for self-management support. Multimorbidity is also more common among socioeconomically marginalized groups compared to more affluent groups, as is the severity of conditions (Silver, 2018). Though multimorbidity has typically been associated with the aging process, growing evidence highlights how it is closely related to environmental factors such as social marginalization and material deprivation (Moin, Moineddin, & Upshur, 2018).

Socioeconomically disadvantaged PWUD and people experiencing homelessness are two groups that experience significant marginalization or social exclusion in developed countries (Baah et al., 2019; Dej, 2020; Kreek, 2011), likely due to multiple, intersecting factors. Firstly, among PWUD and people experiencing homelessness, multimorbidity and severity of health conditions is especially common compared to other patient groups (Arnold-Reed et al., 2014; Brett et al., 2014; Kendall et al., 2017). Moreover, some of the more common health issues among PWUD include conditions often characterized by complexity and stigmatization, especially mental health issues, infectious diseases such as HIV and hepatitis C, and chronic pain (Dassieu, Kaboré, Choinière, Arruda, & Roy, 2020; Kendall et al., 2017). Among PWUD, socioeconomic marginalization has also been strongly associated with risk of overdose (van Draanen, Tsang, Mitra, Karamouzian, & Richardson, 2020). Similarly, people experiencing homelessness tend to have complex and stigmatized health profiles, often including drug use or mental health issues, infectious diseases, and chronic pain, as well as many acute health-related crises (Guirguis-Younger et al., 2014; Vogel et al., 2022). Other chronic physical health issues common in the broader population are also common among these groups (Arnold-Reed et al., 2014; Brett et al., 2014; Guirguis-Younger et al., 2014).

Secondly, in addition to the obviously detrimental factors of low income and unstable housing, marginalized PWUD and people experiencing homelessness are known to experience many other disadvantageous social determinants of health, such as adverse childhood experiences, low levels of social support, and stigmatization and discrimination (Dej, 2020; Mate, 2008; Milaney, Williams, & Dutton, 2018; Paquette, Syvertsen, & Pollini, 2018), which all exacerbate social exclusion and create barriers for daily functioning. For example, stigmatization is a well-known cause of health inequities (Hatzenbuehler, Phelan, & Link, 2013), culminating in increased isolation and reduced resources for coping, including by limiting access to healthcare or housing supports.

Thirdly, these groups often face criminalization due to drug use as well as homelessness, further exacerbating their degree of marginalization (Dej, 2020; Kreek, 2011). Throughout its lengthy history, drug prohibition has made it illegal to be in possession of, use, sell, or even prescribe certain drugs in Canada. Further, there is various “anti-homelessness” legislation in Canada that prohibit panhandling or other acts which are often necessary for survival (Dej, 2020). These laws tend to increase risk factors among PWUD or people experiencing homelessness, resulting in worse health and social outcomes (DeBeck et al., 2017; Dej, 2020).

Finally, it is important to acknowledge the overlap among socioeconomically marginalized PWUD and people experiencing homelessness. For instance, one estimate from a 300-person survey found that 70% of people experiencing homelessness were regularly using drugs (Milaney et al., 2018), while marginalized PWUD commonly report experiences of homelessness or unstable housing (Rowlands Snyder et al., 2021). Thus, members of these two groups are often included within the same samples in studies focused on a range of topics that are relevant to both. In addition, for years now, these groups have faced several overlapping crises in our North American setting, including the opioid overdose crisis and the affordable housing crisis, with the COVID-19 pandemic greatly exacerbating both these crises and resulting in an especially volatile situation for marginalized PWUD and people experiencing homelessness.

Despite marginalized PWUD and people experiencing homelessness having highly complex health and social issues, self-management supports have seldom been targeted toward these groups. This may be due to presumptions about their needs or capabilities. For instance, PWUD may be considered deviants who choose not to self-manage or incapable of self-management due to active drug use (Gowan, Whetstone, & Andic, 2012; Szott, 2015). However, studies have shown that PWUD already employ a variety of self-care strategies day-to-day, often in the context of managing their drug use and practicing harm reduction (Boucher et al., 2017; Drumm, McBride, Metsch, Neufeld, & Sawatsky, 2005; Gowan et al., 2012; Greenspan et al., 2011). One study considered self-care more broadly, finding that street drug users were actively engaged in common self-care practices such as eating healthy or exercising to improve their health (Drumm et al., 2005). Still, further exploration of how personal practices and support services relate to their self-management, including addressing multiple chronic conditions, is warranted among this group.

Among people experiencing homelessness, there is very little literature on self-management, possibly related to expectations that this group has more pressing needs than managing their chronic health issues. However, this notion denotes the predominance of an overly narrow or health-focused view of what self-care activities entail, as the ways that people manage during highly stressful crisis situations (such as homelessness) can also be considered a form of self-care. There may also be a different 'ethos' among the communities of practice that support these marginalized groups, possibly making the currently dominant configurations of self-management less palatable. Still, these groups may have great need for some form of self-management support, thus ensuring they receive such supports in ways that are appropriate to their communities should be considered as one way to help mitigate the health and social inequities they face.

To that effect, some self-management programs may be suitable options for marginalized PWUD and people experiencing homelessness. For example, given the generic focus of the CDSMP and WRAP, these programs may be better than disease-specific programs for people with multimorbidity (Sevick et al., 2007), and the peer-led group format may be suited to tackling social aspects of self-management as well as stigma (Boucher et al., 2019). One author also suggested that the WRAP may be more suitable for individuals requiring support with mental health issues, while the CDSMP may be more suited to physical health issues (Davidson, 2005). However, as the critiques I outlined above suggested, sociostructural barriers may interfere with participation in these programs, or existing programs may require targeted adaptations if they leave priority issues unaddressed (e.g., housing instability, food insecurity, criminalization, stigma). Further, it may be challenging for current institutions to meet the self-care needs of these marginalized groups, given their prior experiences of discrimination, neglect or inadequate treatment in such settings (Dej, 2020; Paquette et al., 2018), thus community-based options will likely be critical.

1.2 Rationale, problem statements, and study objectives

Despite the array of health and social issues that people experiencing socioeconomic marginalization face, there has been limited exploration of how they engage in self-care or mutual care activities to manage these issues, especially among highly stigmatized and socially excluded groups like PWUD and people experiencing homelessness. These negative social and structural disadvantages (including multiple, intersecting crises) may cause immense barriers to people's ability to self-manage, demonstrating a great need for supports. Yet, current self-management programs often appear to be geared toward and utilized by people who have adequate material resources to meet their basic needs (e.g., not experiencing poverty to the degree that it affects their ability to consistently find food and shelter), as well as people who have the means to meet their social support needs (e.g., connections to family, friends, neighbours, or psychosocial care providers).

The overall objective of my dissertation was to examine self-care and mutual care practices among socioeconomically marginalized communities, with the purpose of informing the need for and development of appropriate supports. Further, I aimed to attend to multiple knowledge gaps in the literature – namely, the limited investigation into social factors and equity concerns in the field. This included attending closely to the social determinants of health most relevant to people's social and material resources, particularly housing stability and social support networks. To do this, I first sought to understand current self-management experiences among one such community, including strategies for managing their health issues, as well as barriers and facilitators that affected their capacity to manage (Study 1). The research questions for this study and the first two articles were:

- How do marginalized PWUD self-manage their chronic health issues and drug use?
- What are the barriers and facilitators to self-managing chronic health issues including drug use among marginalized PWUD?

Second, I sought to explore how people experiencing extreme socioeconomic marginalization managed their health and social needs in a unique context (Study 2), asking the following research question:

- How did mutual support occur among people experiencing homelessness within the social context of encampments during the COVID-19 pandemic?

In conducting foundational work with these two marginalized communities, qualitative methods were most fruitful for improving our understanding about their needs, especially given the limited qualitative research on self-management among people experiencing highly complex health and social issues. In the two studies, I conducted qualitative interviews with several groups across multiple settings, with each further analysis iteratively building on the findings of the previous manuscript(s). First, my initial article for Study 1 (Chapter 2) provides a description of the personal self-care strategies of a socioeconomically marginalized group of PWUD, underscoring the holistic nature of their self-care and the need to recognize alternative practices as self-care among this group. Subsequently, my second article for Study 1 (Chapter 3) delves more thoroughly into the social and economic barriers and facilitators of self-management for this group, demonstrating that housing instability was the most prominent hindrance to self-management, yet positive social connections greatly supported self-management. Following these findings, I conducted Study 2 to explore the topics in more depth, set within the increasingly challenging context of the COVID-19 pandemic. In my article in Chapter 4, I render visible the practices of mutual support among a highly socioeconomically marginalized group and how such practices helped people manage their health and social issues, which contrast with the paternalistic notion that people experiencing homelessness cannot care for themselves. Finally, Chapter 5 summarizes the overall findings and discusses the interrelated themes and lessons from the two studies, highlighting the central role of the sociostructural environment, and the value of amplifying the voices of people with lived experience of marginalization. In this dissertation, I outline several complexities and tensions related to the broad issue of individualistic conceptions of self-care, emphasizing the importance of recognizing and incorporating relational practices such as mutual care. Implications for research, practice and policy are discussed, including reflections on methodological challenges and opportunities in qualitative and community-based participatory research contexts.

1.3 Theoretical/conceptual and methodological framework

To address many of the critiques outlined above with respect to exploring self-management among highly socioeconomically marginalized groups, I incorporated several established theoretical or conceptual frameworks to inform study procedures and interpretations. I began by including a holistic, person-centered care perspective that would facilitate centering people's own day-to-day self-management experiences and needs. Patient-centeredness often refers to including the following five dimensions as part of the provider-patient relationship: "biopsychosocial perspective; 'patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'doctor-as-person'" (Mead & Bower, 2000). While person-centered approaches are commonly cited in self-management initiatives (Silver, 2018), holistic approaches are less common. Holistic models typically refer to "whole person" concerns that attend to the "body-mind-spirit" (Frisch & Rabinowitsch, 2019). Given that many self-management approaches are health-focused, it is not surprising to see a lack of focus on other aspects of daily life. Further, some have noted that person-centeredness may occur more in principle than in practice, resulting in patient priorities remaining unaddressed (Rogers, Kennedy, Nelson, & Robinson, 2005). Hence, I anticipated that taking a holistic, person-centered approach in the studies within this dissertation would help illuminate marginalized people's primary concerns and their agency in practicing self-management, as a contrast to persisting paternalistic notions that they must be taught what and how to manage. This recognition of patient agency or autonomy is also central to the history of self-care, as it opposes the passive role of patients in traditional Western medical practice. Thus, my work in this dissertation also goes beyond medical self-care traditions to showcase naturally-occurring mutual care, returning to grassroots self-care and self-help approaches. Acknowledging this neglected historical positioning further enables a more holistic understanding of people's experiences, especially the oft-hidden experiences of marginalized groups.

However, because people’s agency or autonomy is often restricted by external factors, especially among marginalized groups who are subject to many power imbalances, I also followed Ould Brahim’s (2019) recommendation to incorporate the concept of relational autonomy to guide both studies in this dissertation. Relational autonomy was conceptualized due to feminist critiques of the traditional, individual view of autonomy. These scholars highlighted the importance of increasing “attention to the rich and complex social and historical contexts in which agents are embedded” (Mackenzie & Stoljar, 2000), while noting the particular relevance of this conceptualization to marginalized groups whose oppressive social contexts tend to restrict their autonomy. Ould Brahim (2019) argued that adopting this perspective attends to many of the current issues in the self-management field, including the small, short-term effects of self-management interventions, the alignment of self-management with neoliberal principles (e.g., individual efficiency and accountability), and the way self-management has been hindered by the alignment of autonomy with individualism. That is, the traditional view of autonomy “neglects social and material circumstances and the power relations that impact choice, agency, and selfhood” (Ould Brahim, 2019). Further, this author highlights several actions that could support the integration of relational autonomy into self-management research and supports, including to adjust healthcare practices to move beyond internal characteristics and aim to address environmental barriers, shift how a ‘patient’ is conceptualized to include a ‘patient nexus’ (e.g., social ties and corresponding resources), and adopt social ecological models.

In accordance with this perspective, I also drew on several theories to highlight systemic or structural factors that influence experiences, such as social ecological models and intersectionality. The social ecological model positions a person’s individual behaviour as situated within multiple levels of the ecological environment, including a microsystem, mesosystem, exosystem, and macrosystem (e.g., interpersonal, institutions and organizations, community, and structures and systems) (Bronfenbrenner, 1977). While I considered all levels across my dissertation studies, I most closely assessed influences at the interpersonal level, which encompasses people’s social interactions and relationships and is generally the most influential on day-to-day activities.

Relatedly, intersectionality theory adds to understanding the influences of structures and systems of power by emphasizing that people's experiences are "shaped by the interaction of different social locations (e.g., 'race'/ethnicity, Indigeneity, gender, class, sexuality, geography, age, disability/ability, migration status, religion)" (Hankivsky, 2014). That is, people's unique combinations of social factors produce varying experiences of privilege and oppression due to the processes of stigmatization and discrimination (e.g., racism, sexism, classism, ableism). This theory contributed to purposeful recruitment of multiply marginalized individuals in the dissertation studies and aligned well with my methodological choices, all together contributing to the overarching goal of advancing social justice, including through strategies such as meaningful community participation, attending to dynamics of power, exploring the complexities of experience, and ensuring real-world application of findings (Hunting, 2014).

Corresponding with the theoretical and conceptual perspectives, I chose to incorporate the transformative paradigm to facilitate the community-based participatory research and qualitative methods across both dissertation studies. Community-based participatory research has been described as "a partnership approach to research that equitably involves community members, practitioners, and academic researchers in all aspects of the process, enabling all partners to contribute their expertise and share responsibility and ownership" (Israel et al., 2010). Community-based participatory research is more than simply methodology – it is underpinned by specific principles such as collaboration and emancipation, and aligns with the belief "that knowledge is constructed and produced with social and political agendas" (Flicker, 2005). Accordingly, I took a relativist and constructionist philosophical orientation, which also aligns with the qualitative analysis approach I selected for this work. Reflexive thematic analysis was chosen because of its flexibility and appropriateness to the under-explored and policy-relevant topics in my dissertation studies (Braun & Clarke, 2013). Likewise, I applied the transformative paradigm because it is complementary to these methods, as the main tenet highlights the non-neutrality of knowledge due to power differences in society, and thus the importance of engaging traditionally excluded groups in determining the focus of research (Creswell & Poth, 2018; Mertens, 2007). This paradigm outlines the need to attend to cultural complexity, power issues, and social justice by centering and amplifying the voices of people with lived experience of marginalization, and it requires a researcher who “recognizes inequalities and injustices in society and strives to challenge the status quo” (Mertens, 2007). Together, the theories and methods I employed are compatible and well-suited for conducting research with highly stigmatized and disenfranchised groups, particularly as they promote power sharing and the questioning of dominant ideologies with an aim of co-creating knowledge to support social change.

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Chapter 2: Component Article 1

“The drug use unfortunately isn’t all bad”: Chronic disease self-management complexity and strategy among marginalized people who use drugs

The aim of this study was to explore the question: How do marginalized PWUD self-manage their chronic health issues and drug use?

This study was approved by Bruyère Research Institute (M16-19-027) and University of Ottawa (H-10-19-5175) Research Ethics Boards.

Appendix 1 is included following the references for this article, containing one supplementary table and one supplementary figure.

Contributions of co-authors: For study 1, Lisa Boucher led the conceptualization, study design, analysis and interpretation, and writing of the two journal articles. Drs. Kendall, Liddy, Leonard, Presseau and MacPherson provided guidance throughout the study, as did the Community Advisory Committee members (Alana Martin, Dave Pineau, Christine Lalonde, Nic Diliso, and Terry Lafleche). Drs. Shoemaker and Fitzgerald also supported conceptualization and analysis. Lisa Boucher wrote the complete first draft of the articles and all authors provided feedback prior to submission.

Published in manuscript form as:

Boucher LM, Shoemaker ES, Liddy C, Leonard L, MacPherson P, Presseau J, Martin A, Pineau D, Lalonde C, Diliso N, Lafleche T, Fitzgerald M, Kendall CE. (2022). “The drug use unfortunately isn’t all bad”: Chronic disease self-management complexity and strategy among marginalized people who use drugs. *Qualitative Health Research*, 32(6), 871-886.

The electronic version of this article is the complete one and can be found online at: https://doi.org/10.1177/10497323221083353

Abstract

Self-management programs improve health outcomes and self-management is recommended for chronic conditions. Yet chronic disease self-management supports have rarely been applied to people who use drugs (PWUD). Thus, our objective was to explore self-management experiences among marginalized PWUD. We used community-based participatory methods and conducted qualitative interviews. Participants self-identified as having long-term and past year experience using non-prescribed drugs, one other chronic condition, and socioeconomic marginalization. We analyzed the data using reflexive thematic analysis. Although many participants considered drug use a chronic health issue, self-medicating with non-prescribed drugs was also a key self-management strategy to address other health issues. Participants also described numerous other strategies, including cognitive and behavioral tactics. These findings highlight the need for a safe supply of pharmaceutical-grade drugs to support self-management among marginalized PWUD. Self-management supports should also be tailored to address relevant topics (e.g., harm reduction, withdrawal), include creative activities, and not hinder PWUD's agency.

1. Background

Marginalized people who use drugs (PWUD) tend to experience complex health conditions characterized by chronicity and multimorbidity, as well as intersectional stigma and disparities related to social determinants of health (Biancarelli et al., 2019; Boucher et al., 2017; Dassieu, Kaboré, Choinière, Arruda, & Roy, 2020; Degenhardt et al., 2013; Paquette, Syvertsen, & Pollini, 2018). They have poorer health outcomes and lower life expectancy than the general population (Degenhardt et al., 2013). In Canada, the Expanded Chronic Care Model (E-CCM) (Barr et al., 2003) has been adopted for the prevention and management of increasing prevalence of chronic disease (Ontario Ministry of Health and Long-Term Care, 2007). However, despite calls for the treatment of substance use disorders as chronic conditions (Dennis & Scott, 2007; Kim et al., 2011, 2012; O'Connor, 2013), they are often not considered within chronic disease initiatives.

One domain of the E-CCM pertains to self-management (Barr et al., 2003), defined as "the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with the medical management, role management and emotional management of their conditions" (Adams, Greiner, & Corrigan, 2004). Recognizing that people with health conditions must practice self-management day-to-day outside of the healthcare system, self-management support aims to increase their confidence, motivation, knowledge, and skills to cope well with the impacts of illness (Liddy, Blazkho, & Mill, 2014; Lorig, 2002). Self-management programs have been shown to improve health behaviors, health outcomes, and quality of life across chronic conditions (Allegrante, Wells, & Peterson, 2018), including for some disadvantaged groups (McDonald et al., 2004), and people with severe mental health issues (mhca Care Management Bulletin, 2015) or HIV (Boucher, Liddy, Mihan, & Kendall, 2019), common comorbidities with substance use disorders (Kendall et al., 2017). Regardless, disadvantaged populations have less access, lower participation, and greater attrition from self-management programs, despite having greater multimorbidity and worse outcomes (Mills et al., 2014), and there remains scarce research on supporting self-management among people with complex chronic diseases (Sevick et al., 2007).

One explanation for why self-management support has rarely been explicitly applied among PWUD is because of (mis)conceptions that they are either “deviants” who choose not to self-manage or that active drug use renders them incapable of self-management (Gowan, Whetstone, & Andic, 2012; Szott, 2015). Prior studies describing self-care among PWUD have mainly focused on how people manage their drug use, especially the role of harm reduction practices (Boucher et al., 2017; Gowan et al., 2012; Greenspan et al., 2011), while other studies have focused on self-managing specific health issues (Holt & Treloar, 2008; Smith, Robinowitz, Chaulk, & Johnson, 2014; Wilson et al., 2018). However, one qualitative study of 28 people in Florida, USA, considered self-care more broadly, finding that street drug users actively engaged in self-care practices such as eating healthy or exercising (Drumm, McBride, Metsch, Neufeld, & Sawatsky, 2005).

Ensuring this community has access to adequate self-management supports should be a priority. Enhancing self-efficacy is the backbone of many self-management programs – that is, enhancing people’s belief in their capacity to perform self-managing behaviors (Bandura, 1977). Yet, while associations have been found between low self-efficacy and greater frequencies of drug use and relapse, there are also few interventions to improve self-efficacy among PWUD (Kadden & Litt, 2011). In addition, given PWUD’s multimorbidity and complex needs, generic chronic disease self-management programs may be more effective than disease-specific programs (Sevick et al., 2007). Regardless, to identify or adapt existing self-management initiatives and to develop new ones for PWUD – as with any under-researched population on a given topic – an understanding of their perspectives, experiences, and needs pertaining to self-management is first required (Lorig & Holman, 2003). Thus, the aim of this study is to explore the question: *How do marginalized PWUD self-manage their chronic health issues and drug use?*

2. Methods

2.1 Theoretical/conceptual frameworks and methodological approach

To accomplish our study aim, we conducted in-depth qualitative interviews and incorporated a holistic, person-centered approach that would highlight the agency of PWUD. Holistic approaches tend to be concerned with the “whole person”, attending to the “body-mind-spirit” (Frisch & Rabinowitsch, 2019). Patient-centeredness is often conceptualized in terms of provider-patient relationships, involving five dimensions: “biopsychosocial perspective; ‘patient-as-person’; sharing power and responsibility; therapeutic alliance; and ‘doctor-as-person’” (Mead & Bower, 2000); though we employ the term “person” instead of “patient” because it “directs energy to those managing their conditions in their own way, as it were ‘outside’ the health system”, which better includes marginalized groups and thus health equity concerns (Pulvirenti, Mcmillan, & Lawn, 2014). Holistic and person-centered approaches are well-aligned (sometimes even paired), and notably, both have been conceptualized as important principles for optimizing self-management/self-care (Pulvirenti et al., 2014; Pyles, 2020). However, past research has found patient-centeredness to be limited within clinical chronic disease self-management initiatives, especially with respect to valuing patients’ experiential knowledge of self-management strategies or ensuring meaningful shared decision-making (Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011; Rogers, Kennedy, Nelson, & Robinson, 2005). Further, providers may incorporate more narrow interpretations of self-management than patients and experience organizational constraints to implementing holistic, patient-centered care (Rogers et al., 2005). Acknowledging these issues, as well as the likelihood they are exacerbated among marginalized groups, we aimed to understand PWUD’s own conceptualizations of their illness and self-management experiences.

Accordingly, we also incorporated a transformative framework meant to amplify the voices of marginalized groups toward addressing social justice (Creswell & Poth, 2018; Mertens, 2007). The transformative paradigm highlights the importance of interrogating privilege and power structures and attending to cultural complexity (Mertens, 2007). We recognized the disadvantaged social positions of our participants and the need to better understand their complex lived realities – especially due to our focus on PWUD who are socioeconomically marginalized, but also their identification with other marginalized groups (e.g., racial or gender minorities). This led us to focus on creating a non-judgmental space where participants’ own preferences and most important concerns could come to the forefront. This information is pertinent because, while patients in general may be recognized as experts on their own self-management (Lorig, 2002), marginalized groups are often left out of decisions that affect them.

Complementarily, we established a community-academic partnership through the pragmatic use of community-based participatory research (CBPR) (Israel et al., 2010; The SAGE Qualitative Research Kit, 2007). CBPR emphasizes collaboration and meaningful participation of community stakeholders, with goals of co-learning and taking action for social change (Flicker, 2005). CBPR methods were critical for this study because expert consensus has highlighted the importance of meaningfully engaging people with lived experience in self-management support initiatives, as well as enhancing health equity in the field (Mills, Brady, Jayanthan, Ziabakhsh, & Sargious, 2016). Thus, improving consultation with marginalized groups can help to meet these goals and increase the relevance of self-management supports.

Overall, we anticipated that some marginalized populations' experiences may not reflect the current self-management frameworks commonly applied to general populations, including by not incorporating a holistic and person-centered approach that attends to the complex needs of these groups. We considered this exploratory study to be a first step toward determining which aspects of self-management initiatives may or may not be appropriate or useful for marginalized PWUD, with the larger purpose of advancing knowledge that can address the health inequities this group experiences.

2.2 Research location and team

The study took place in Ottawa, Ontario, Canada, and was approved by Bruyère Research Institute (M16-19-027) and University of Ottawa (H-10-19-5175) Research Ethics Boards. In accordance with CBPR practices, we engaged community members throughout the research process. The lead author drew on prior experience working in a CBPR capacity with the intended population and enlisted key community members with lived experience of drug use issues, other chronic health issues, and socioeconomic marginalization, and who were well-known and respected among the local community. Due to pervasive stigma and prior negative experiences, marginalized PWUD often distrust care providers or other authority figures; hence, well-connected and trusted community members were crucial in this study (Newcombe, 2013).

At the onset of the study, we engaged one community member with lived experience as a Community Research Coordinator. This individual had extensive experience from prior research studies in this type of role, which in this study involved identifying four other community members with lived experience to participate on a Community Advisory Committee (CAC) and helping to coordinate and facilitate their activities. The primary roles of CAC members were to provide guidance on study methods, develop research tools, conduct recruitment, support analysis and interpretation of findings, and support knowledge translation. We selected community members based on: 1) diversity in past research training or experience; 2) representation of diverse characteristics and experiences among the study population; and 3) current engagement in various capacities with community organizations. To promote consistency in this study, they also received (new or refresher) training in research ethics, qualitative methods, recruitment, data analysis, and knowledge translation. CAC members signed confidentiality agreements and received honoraria for their work.

2.3 Interview guide development

We held CAC meetings to create a semi-structured interview guide. Questions broadly investigated how people's chronic health issues and drug use influenced each other, as well as their motivations, needs, and experiences in regard to personal self-management practices and receiving self-management supports. Recognizing the breadth and complexity of the topic, CAC discussions included time focused on ensuring the language was appropriate for the community. For instance, we adjusted the phrasing of questions to avoid using only the term 'self-management', instead asking how people 'manage' their long-term health issues or using the more familiar term 'self-care'. Our key questions were broad, such as "What do you do on a day-to-day basis to manage your chronic health issues?" We incorporated a funnel approach in which open-ended questions were asked initially to encourage free-form conversation on most topics. If certain questions of interest did not arise naturally, they were asked explicitly before the end of the interview (Morgan, 1996). We reviewed our interview process throughout – adapting questions organically to address participants' challenges in interpretation and new issues they highlighted as important to self-management – and overall ended up using a more unstructured interview style to obtain the most relevant information. Our interview guide is included as supplemental material.

2.4 Sampling and recruitment

We selected eligibility criteria through CAC discussions, specifying that participants must self-identify as having: 1) long-term experience using non-prescribed drugs (i.e., illegally-obtained drugs or prescription drugs used not as prescribed, beyond exclusively cannabis), including in the past year; 2) one other long-term (chronic) health issue; and 3) current financial difficulties (i.e., to meet our definition for "socioeconomic marginalization"). While PWUD also experience other types of marginalization, we chose to focus on those who were socioeconomically marginalized (Richardson et al., 2015). This was mainly due to the CAC's concerns about potentially grouping PWUD who struggled with financial instability with those who did not, as they anticipated unique self-management experiences and needs. Additionally, this focus helped us unify our sample around one type of marginalization. We aimed for a purposeful sample of participants using the sampling strategy of maximum variation in order to identify a diverse range of perspectives (Palinkas et al., 2015). The CAC determined as the most relevant factors: age, sex and gender, sexual orientation, ethnicity, drug use characteristics, common health issues in the community, common marginalizing experiences (e.g., housing instability, sex work, incarceration), and people's level of engagement in services.

We used a peer-led, street-based recruitment approach, which has successfully been employed in prior studies among this community (Boucher et al., 2017). With community input, we identified "hot spot" locations for in-person recruitment, mainly focusing on areas of the city near our planned interview locations to facilitate accessibility. On each data collection day, one of three community researchers led the recruitment process. This procedure capitalized on the community researchers' trusted position in the community to facilitate the lead author's introduction to and rapport with potential participants. Individuals recruited were typically scheduled to participate in an interview within a short timeframe to reduce no-shows. We recruited participants between December 2019 and March 2020, at which time data collection was suspended due to the COVID-19 pandemic.

2.5 Data collection and analysis

We conducted fifteen individual, in-person qualitative interviews with recruited participants, scheduled so that we could conduct ongoing, iterative analysis, refining our recruitment strategy and interview guide throughout data collection. Interviews took place at four community-preferred sites, including several community-based organizations frequented by PWUD in our setting. The lead author obtained written informed consent and conducted all interviews. We administered a brief questionnaire to collect sociodemographic information from participants, with results summarized descriptively in Supplemental Table 1. Participants were compensated CAD 30.00 for their time.

All interviews were recorded and transcribed verbatim, with hand-coding and NVivo software used to code the transcripts (QSR International Pty Ltd, 2013). Audio recordings of the interviews had a mean length of 1 hour and 13 minutes (range = 39 minutes to 1 hour and 49 minutes). The lead author (trained in multiple research methods through psychology and epidemiology) fully coded all transcripts, while a qualitatively-trained medical sociologist coded half of the transcripts, and a community researcher coded two transcripts and reviewed codes of all prominent categories to provide cultural interpretation. We used an inductive approach, with all codes and themes generated from data analysis rather than identified in advance. Major and minor themes, and relationships among them, were brought to discussions with both academic and community researchers, and further adjustments were made to reflect insights gained.

We used the qualitative research approach of reflexive thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2019a; Braun & Clarke, 2020). This involved considering both manifest and latent content during data analysis, with a focus on identifying the patterns and threads (themes) across the data. We also adopted constant comparison and line-by-line coding to enhance validity of our findings (Creswell & Poth, 2018). Aligning with reflexive thematic analysis, each reflexive iteration allowed us to increase our focus and progressively make meaning (Srivastava & Hopwood, 2009). A focus on achieving data saturation was not required nor conducive to this type of analysis (Braun & Clarke, 2019b). Rather, we employed the concept of "information power" to determine that the sample data contained adequate information to provide new insights relevant to our research question (Malterud, Siersma, & Guassora, 2016). In particular, we had sufficient information power due to the very strong quality of the interview dialogue, bolstered by the interviewer's extensive familiarity with the population and research topic, as well as our incorporation of theory in the study design and a highly purposive recruitment strategy that led to specificity in the sample.

To further enhance quality and rigor in our methods, we considered Guba's (Guba, 1981) four criteria for trustworthiness: credibility, transferability, dependability, and confirmability. In addition to constant comparison and line-by-line coding, we used the following strategies during data collection and analysis to meet the criteria: tactics to enhance or detect informant honesty, recording iterative reflective notes, debriefing between the interviewer and experts on and off the research team (including people with lived experience), and using thick quotes in dissemination to allow the reader to make their own judgements (e.g., credibility); collecting and reporting rich contextual details (including on setting and participants) to allow assessment of whether findings may be applicable to other contexts (e.g., transferability); documenting challenges and discussions to maintain a decision trail, and reporting our methods in detail to facilitate repeatability (e.g., dependability); and acknowledging personal biases and assumptions (including examining our social positions and power), and providing in-depth description of shortcomings (e.g., confirmability) (Noble & Smith, 2015; Shenton, 2004).

3. Results

3.1 Portrait of self-reported chronic health issues

When asked to describe their chronic health issues, participants detailed a wide range of concerns, including mental health issues, primarily pain-related issues, infectious diseases and their comorbidities, and other physical health issues (e.g., colitis, chronic obstructive pulmonary disorder). The most frequently reported chronic physical health issue was pain, which was diverse in terms of severity and source or type (e.g., feet, back, migraines, arthritis/joints). A majority of participants also reported infectious diseases (e.g., HIV, hepatitis C). While all participants reported having current or previous mental health symptoms or conditions, only approximately half described these as chronic. The most commonly discussed mental health issues included depression, anxiety, and post-traumatic stress disorder. Many participants mentioned having experienced significant symptoms, including suicidal thoughts or attempts. Participants often described mental health issues in terms of having too much “stress” or being “overwhelmed,” rather than as specific diagnoses (although sometimes they did both). Similarly, they often described these issues as directly related to previous or current negative (including traumatic) life experiences.

Extensive multimorbidity and comorbidity were common, including issues related to aging or long-term disease progression (e.g., with HIV). Participants often mentioned a number of acute and recurrent symptoms and diagnoses such as frequent infections that, in their entirety, were experienced as chronic health concerns. For instance, in response to being asked to list chronic conditions, one participant said: *“Like, I go through a series of colds and like, flulike symptoms, which makes me overall pretty paranoid with other viruses that might be out there. So I get kind of confused, because one day I’ll be fine, the next day I won’t be fine...”* Participants had trouble separating their descriptions of acute versus chronic health issues, partly because the former often progressed to the latter. Participants typically did not prioritize one health issue over others (including drug use), instead thinking about their health and self-management in a holistic way.

All participants had many years of experience using drugs and most described a preference for a certain type of drug – usually either “uppers” or “downers” (i.e., crack/cocaine or crystal meth vs. opioids) – although they were still polydrug users. Current or past injection drug use was common, as was smoking, snorting, and ingesting pills. As for legal "recreational" drugs, several participants reported regular alcohol use, a substantial number used cannabis, and the majority smoked cigarettes. While cannabis has only been legal in our setting since October 2018, participants were using it well before this time.

All but one participant considered their non-prescribed drug use to be a chronic health issue, even those who felt they were currently controlling their use well but had more issues with it in the past. As one participant responded: *"I do, because look if somebody'll put it in front of me and I can do it, I would do it, I will do it. … I do see it as chronic because I can never imagine myself being completely abstinent. I don't really want to be completely abstinent."*

However, some participants clarified that they thought of their drug use as different from their other chronic health issues, for instance describing it as more episodic or not as much of an issue if it was well-managed. Further, some participants considered their drug use a chronic health issue intricately related to one of their other health issues (e.g., comorbidities), especially mental health or chronic pain: *"So that's another chronic health issue is just the addiction and the like depression… Yeah, I get a phone call and it's like I don't want to answer the phone, it feels overwhelming. I have to be high to do anything."*

Supplemental Figure 1 provides a summary depiction of participants' overall health concerns, highlighting the most common or impactful examples they discussed.

3.2 Themes generated from data analysis

Our analysis identified two overarching themes depicting participants' lived experiences of self-managing their chronic health issues including non-prescribed drug use, each with four sub-themes: 1) Participants' non-prescribed drug use interrelated with chronic health issues and self-management in complex ways; and 2) Participants employed many personalized strategies similar to those in generic self-management initiatives.

3.2.1 Participants' non-prescribed drug use interrelated with chronic health issues and self-management in complex ways

Participants' experience of their drug use as a chronic health issue was complicated by the fact that using drugs was one of their key strategies for self-managing their other chronic health issues. Other complications for participants' self-management included the detrimental symptoms they experienced when they did not have their drugs or when they were using in unstable ways. Participants recognized these complexities and attempted to stabilize their drug use through using harm reduction strategies.

3.2.1.1 Drug use as self-medication for other health issues

Self-medicating with non-prescribed drugs was the crux of participants' self-management regimen for their chronic health issues, and often the first practice they mentioned, as demonstrated in this exchange:

> *Interviewer: What do you do on a daily basis to manage those different health issues?*
>
> *Participant: Well, it depends on which health issue I'm having that day, I guess. …For the arthritis, I will tend to find some purple [fentanyl], and usually, when I do the purple, it'll relieve a number of symptoms that I'm having, such as like, if I'm having cold sweats or if my muscles, joints are hurting... Which, then for the crack cocaine or the cocaine or whatever…that helps like, my mental issues like, if I'm feeling depressed or if I don't want to think at all…*

In describing how they used non-prescribed drugs to treat mental and physical health issues, participants chose certain drugs to help with different symptoms. Opioids were most frequently discussed and considered helpful for pain (especially physical pain, but also emotional pain). Stimulants were mainly described as useful to treat mental health issues, although some participants noted they could help with physical health issues too by allowing them to forget for awhile. As a participant with anxiety explained:

> *Participant: I'm moving at a sluggish pace because I'm just – I don't have what I would almost call my medicine, right, at this point.*
>
> *Interviewer: OK, makes sense. So, what would that be then? Like, which drugs…*

> *Participant: Oh, crystal meth is what I normally use. …it's what works best with my brain chemistry. …the drug use alleviates a lot of the anxiety, right? …The drug use unfortunately isn't all bad. It gives you confidence and gives you motivation sometimes. Gives you the energy you need to go through your day and get – accomplish what you need to accomplish.*

Participants also described their self-medication practices in ways that indicated their goal was to mitigate their symptoms rather than to get high: *"Because I wasn't addicted to the stuff... I was doing it on my own terms, I'd do a shot and if I felt the shot like I wouldn't do it for two days because…sometimes I don't get a migraine every day, so it's just when I need it..."*

Participants reported that cannabis was the most beneficial drug they consumed as self-medication. They noted that cannabis helped with managing symptoms of a wide variety of health issues, in particular gastrointestinal issues, chronic pain, sleep problems, and emotional dysregulation. One participant described the substantial positive influence of cannabis on his ability to self-manage:

> *…weed has probably played the biggest role in my life, it was for medication… it just helps me a lot with my mental health and my physical… I will forget to smoke weed because I don't crave it like that. …then I do [smoke] and all of a sudden it's like OK, let's get a job… [it] makes me a lot better at taking care of myself. …I'm like dude, you should probably drink some water, that type of thing. …it takes me out of the part of my brain that I let the negative voice happen… and then I can focus on taking care of myself.*

However, participants noted having trouble affording cannabis in addition to affording their other drugs and basic needs. Furthermore, many preferred using non-prescribed drugs to self-medicate over the use of mental health medications. For instance, one participant who used opioids to help cope with depression and difficulty sleeping, described the negative experiences she had had with prescription medications:

> *Participant: …I don't like to take anti–depressants, I don't like Seroquel and all that.*
>
> *Interviewer: So you're not on any mental health medications?*
>
> *Participant: Valium and all that – clonazepam or clonidine or…*
>
> *Interviewer: Okay, have you tried any of them?*

> *Participant: Yeah, I don’t like any of them, no, they make me feel worse.*

3.2.1.2 Lacking access to drugs interfered with self-managing and health

Participants expressed detriments to their self-management abilities and health overall when they did not have consistent access to their drugs. Typically, this pertained to opioid users and the challenges of physical withdrawal, which was compounded by the exacerbation of chronic pain among some participants: “*I'm always having a bad day. My legs already hurt right? But just the level of hurt right? So nothing in my system – like I'm almost in tears.”*

Participants also explicitly noted that withdrawal interfered with self-managing their other health issues: “*And I wouldn't change my bandages unless – if I was dope sick I'd leave it on forever. Because it hurts so much.”* They also discussed the importance of having strategies to avoid withdrawal: “*Like I always have to plan ahead a little bit, every day, to make sure that in the morning that I’m going to have enough [drugs]…so at least I can get a start, start my day…”*

Similarly, participants who used stimulants described experiencing negative symptoms when they did not have their drugs. As one crystal meth user explained, the most challenging aspect of their drug use was when they lacked access to it:

> *Interviewer: Do you get any symptoms from the drug use that are negative? You already mentioned like, positives from it…*
>
> *Participant: Well, it’s only if I don’t have it. Like, today for example, like, I’m low energy, I’m not really feeling like myself completely, you know?*

3.2.1.3 Desire to improve stability of drug use to improve health

Participants often noted that their self-care goals included stopping or better managing their drug use. A few described how they had accumulated worsening chronic health issues over time or as they aged, and subsequently their drug use became more difficult to sustain without further worsening their health, as one participant explained:

> *And then the emphysema is what actually was my brick wall because I couldn't do it anymore. I couldn't smoke crack anymore, I couldn't smoke cigarettes anymore, I couldn't walk across the street anymore without, you know [shortness of breath sounds]. … With the opiates, it took me longer to stop… I think it had a lot to do with the fact that I really messed up my veins.*

Some participants described how drug use interfered with self-managing their other health conditions, especially if they were experiencing unstable drug use. As one participant noted:

> *A lot of the health issues I have is from HIV and the side effects, but I think the using of the illicit drug isn't helping. …When you're using the drugs, your immune system is more low. I'm not eating because you don't want to eat. I try to take multi-vitamins and vitamin C, but then if you don't have any substance in you they're just not absorbed. …So, I mean, I know all these things, but it's hard to practice when you're [using].*

Thus, participants typically desired to better control their drug use with the aim of improving the prognosis of other health conditions, as one participant described: *"But [hepatitis C]'s the one I'm worried about now because I don't want to drink as much as I want to. I mean, I want to drink but I can't. I have to watch my liver enzymes…"*

Participants also noted having made progress with respect to using drugs in less detrimental ways, such as how replacing the drugs that caused them more problems with other drugs could be beneficial for managing their health overall:

> *I don't want to go through life without ever catching any kind of a buzz but I don't want it to consume me and cost me everything and kill my health… So a couple of drinks here and there, eat a pot cookie, I'm good with that, you know? That's about where I'm finding myself now. …now that we're talking about things like the psilocybin and the edibles and stuff, like I really should be focusing more on that. …you know, just give you a little lift and be safer and be beneficial in other ways too, like therapeutic value…*

Furthermore, participants were aware of and constantly weighed the pros and cons of their drug use with respect to their health, making efforts to balance these. Most did not consider complete cessation of drug use to be a solution, as one participant with extensive multimorbidity expressed:

> *Well, I'm kind of like, confused with like how long my drug use is either going to let me live versus the healthcare that I'm getting. If I were to quit drugs would I live longer, or is it the drugs that I'm taking now with the care that's making me live longer? Because you know, if you do something for a long time and then you take it away, you – your body can either like – need it, or your body can get really, really sick without it…*

3.2.1.4 Employing harm reduction practices to manage drug use

Overall, harm reduction was clearly an important part of PWUD's self-care regimen, and central to managing their drug use. Yet given the context of the longstanding overdose crisis in our setting (Public Health Ontario, n.d.), it was not surprising that much of the harm reduction practices they discussed pertained to reducing risk of overdose. These practices were ultimately about survival, as many had overdosed themselves or lost loved ones to fatal overdose, yet their worries about dying and grief interfered with their mental health. People described using supervised injection services, keeping naloxone on them, using with other people nearby, using pharmaceuticals or avoiding street drugs, buying from trusted drug sellers, avoiding fentanyl, and testing drugs using test kits or by taking small first doses.

Other key harm reduction practices included using in moderation, tapering drugs to avoid or reduce withdrawal effects, avoiding certain drugs, replacing drugs with less harmful (or even beneficial) ones, using sterile equipment, using less harmful routes of administration, and saving doses to avoid having to go without at future times. For example, as one participant described:

> *…if somebody gives it to me for free, okay, sure I'll do a little puff and I won't do it until after I've had lunch kind of thing, whereas before I was doing crack 24 hours a day almost. … At least now I've slowed down and I actually have time to think…like that's why I think it's better now, like that's why my creativity has really been coming back more bit by bit…*

Many participants also noted how a safe supply of pharmaceutical-grade drugs would improve their ability to practice self-care. Although this desire was most prominent among people currently obtaining opioids from the street, participants using other types of drugs also described how a safe supply would not only reduce their likelihood of death, but help to address their challenging financial situations, thus allowing more time to focus on their health issues:

> *Interviewer: …if you could get any support or service that you're not getting, what would that be?*
>
> *Participant: It would be something like safe supply. … Now that I see some of my friends on it I'm like, jealous, cause they have more time to figure out their problems and they have more times to themselves because they're not sitting there chasing the drug all the time or chasing after money…*

Another participant described how safe supply could be a starting point from which marginalized PWUD could build the foundations necessary to develop self-care practices:

> *But I think ultimately one of the first ways that we can have people start getting some security, like right now if you're on the street and you're hooked and you're homeless and all that, if all you could get was a safe supply of clean pharmaceuticals that wasn't going to kill you, that doesn't fuck with your mind and neurology and biology the way that this other bad drugs do, it would be a good start. Because then maybe they could start thinking oh well, now that I'm secure in this, now can I think about getting a place, now can I think about seeing a doctor, now can I think about addressing this health issue and that health issue...*

3.2.2 Participants employed many personalized strategies similar to those in generic self-management initiatives

Participants described many different types of strategies, which they often used in a holistic manner, not only to cope with current health issues but also for preventive purposes. As one participant described, cultivating an extensive self-care regimen had highly positive effects on her health:

> *…now I have a little skin care routine…I make sure I get enough sleep. I'm choosing, more wisely what I eat. I'm more thoughtful and mindful about, what I want to do to not only protect my health and improve it but to prevent stuff. … And the more that I'm developing self-care habits, the proof is in the pudding because the difference can be felt and it's amazing to me.*

3.2.2.1 Most commonly recognized self-management behaviors

Several of the strategies participants described are the most well-recognized self-care strategies in general, aligning with people's basic needs, and commonly addressed within self-management programs, such as nutrition and physical activity (Lorig et al., 2013). A few also discussed the importance of sleep, as well as personal and living space hygiene. Whether participants prioritized certain activities over others depended on which ones helped relieve the symptoms of their specific chronic health issues. For instance, nutrition was central to a participant with colitis, while monitoring sleep was a key strategy for a participant with bipolar disorder. However, many participants noted that they struggled to perform these strategies. For example, one participant said: *"We don't eat proper anything."* Others mentioned how obtaining food prior to their drugs was a self-management strategy: *"I'll make sure, like, I have food before drugs."*

As for physical activity, several participants mentioned doing yoga or going to the gym. Participants also made it clear that they obtained much exercise through walking to conduct their typical daily activities, including obtaining their drugs: *"…cause you got to think about if you're looking for something, you're stuck downtown, you're walking and you're walking…you walk a lot. I walk like all over the place…"*

3.2.2.2 Cognitive and behavioral strategies, especially creative activities

Participants employed many cognitive and behavioral strategies to manage their health issues, including techniques for relaxation (e.g., deep breathing, meditation, visualization, gardening, knitting, hot bath), mindfulness, positive thinking, distractions, being in nature, keeping busy, developing a routine, reflecting on patterns between behaviors and symptoms, prioritizing, committing to an action, acknowledging limitations, and taking responsibility. For example, one participant described her relaxation process in detail:

> *So if I feel like I'm getting too stressed out I imagine with every breath in I take, I am breathing in, taking all the toxins and all the stress I have, when I'm breathing it in I imagine that I'm storing them in my inside when I breathe in. Hold it in for eight counts, and then I exhale all that garbage out as hard and as loud as I can. It works.*

Similarly, focusing on spirituality was an important strategy among participants, especially to help manage mental health issues. For some this involved following the practices of organized religion or engaging with certain spiritual groups, whereas for others it was described as a more personal or introspective journey. Some participants reported regular engagement with spiritual activities – *"…my typical day is, I pray a lot… So, that's part of the self-care, a little spirituality."* – while others mentioned recent attempts to further embrace these kinds of strategies. Indigenous participants highlighted cultural-spiritual traditions as meaningful for their mental health and desired more opportunities to engage in these. As one participant described, the ability to spend time in nature would be beneficial: *"Yeah, it would be so good to get out of the city once in a while, stuff like that, like go sit by a lake or a river or ocean. You know, burn and cook things with a fire like my grandfather used to. I would love that but I…I have no access."*

A few participants also discussed the importance of time management. While some noted how they mainly focused on the present day, one participant explained how planning her days in advance led to improvements in managing emotional symptoms:

> *…my whole life did everything by the seat of my pants, couldn't plan 30 seconds ahead. … But now I live by my calendar. … And it helps me psychologically to write things down, like this is what I've got to do tomorrow. …and then there's way less stress because like I know what I'm doing, when I'm doing it. And I still can be spontaneous and flexible but I just really am enjoying how it makes my life easier and I'm not as anxiety ridden as I ever*

> *used to be all the time about stuff… And so I feel good about that because I think that's part of self-care is managing my time so that I'm not freaking out all the time…*

The most prominent type of cognitive and behavioral strategies involved having creative outlets to cope with the negative emotional effects of health issues. Many participants noted that they engaged in (or wanted to engage in) arts-based activities, including music, fine arts, visual arts, performance arts, decorative arts, cosmetic arts, and making handmade crafts. As one participant said: *"Music… It takes a lot of stress away."* They also reported how these practices were beneficial and motivating for better managing drug use:

> *And I'm just in a transitional phase. It's really weird because I'm starting to not abuse drugs again. And getting back into music… I'm trying to rediscover parts about me that I still want from before I used, you know? Cooking, like the cooking thing, I was working in fine dining.*

However, participants whose drug use was more unstable tended to have trouble engaging in these desired activities:

> *Oh yeah, I miss playing my guitar all the time and tattooing and drawing and stuff. … When I quit doing drugs I need to be doing something or I'll be out making money to get drugs, getting drugs, or getting high. Like my life revolves around dope. … That relieves a bit of stress, and I've been playing for over 30 years right?*

Participants also highlighted how these creative activities went beyond simply managing emotional dysregulation, as they were often central to their future goals and to cultivating a fulfilling life: "*I'm an artist and I really want to get back into…that sort of thing. And I just want to like, launch back into a lifestyle that I can be proud of."*

3.2.2.3 Seeking out healthcare resources

Several participants noted how they felt the need to be proactive in monitoring their health issues and were aware of supports available: *"I know where to go and how to get supports if I need them. Just pick up a phone or just walk into a place and say hey, I could use some of this or that."*

Other participants were less familiar with how to obtain supports, but still indicated that they knew it was important to seek them out: *"I know I need somebody to help right? So I can't do it on my own obviously, or it would be done so – and I am going to – I got to start taking care of myself better."*

Some participants had not been well engaged in care but as their health issues worsened they had begun to obtain support: *"Well right now, I'm getting scared that I'm going to end up in the home, so that's what's motivating me, I guess, is fear. … I just finally got a family doctor last week. … I did about ten years without one."*

In addition, participants often sought formal treatment to help manage their chronic pain, mental health issues, or drug use, with limited success. Many had tried opioid agonist therapy, yet some were unhappy with it and tried to wean themselves off. Participants unwilling to use opioid agonist therapy noted limited options: "*And I've been to, you know, [a clinic] a few times to see the doctors there. …just to talk about different alternatives. But you know, their alternatives, it's either methadone or Suboxone, and I don't like them both."*

More rarely, prescriptions were available to treat other types of drug use, including alcohol, nicotine, and other stimulants. Sometimes participants obtained prescriptions second-hand through other people.

Pain-related supports were especially hard to come by for PWUD, and participants reported this as a priority gap in managing their health. One participant highlighted how better access to pain medication would help him maintain a more consistent schedule:

> *But if I had a script I'd take them normally, and then I'd have them on schedule because when I buy them I don't get that much and I don't have enough money to get them, so I have to space them out. And it's hard to say which migraine is going to be the worst… so I'd rather try to get a script so I can like take them regularly… so I can live my life.*

3.2.2.4 Adhering to healthcare guidance

Some participants highlighted the importance of adhering to healthcare regimens for managing their chronic health issues, including taking prescription medications as directed or consistently attending appointments with healthcare providers: *"One pill every day for ever... But I go to the doctor regularly and get bloodwork done and they do my CD4, CD8 and my liver and everything like that. … It's important to me to know what my counts are because I need to know. Like, my viral load for HIV is undetectable. Which is good."*

Participants also described having multiple medications for their different health issues, and the importance of having a routine for remembering to take them: *"I mean, it's – you can remember taking your medication every day and that but now I'm on medication in the day time; I'm on medication at night time, medication at supper time. So like it's – I got to be on a regular base with my medication."*

Regular engagement with providers was also a strategy for preventing further health issues, especially among those who were thinking about aging. Some participants noted how they followed non-pharmacological instructions from their providers, such as improving nutrition and physical activity, partly because they wanted to avoid the need for more medications:

> *Because in my mind I feel that has a little impact because my bones are really hardening this year. And then also, the cholesterol, it's been like over 20 years now that I've kept just borderline, for 20 years, on diet and exercise. …it was recommended to diet and exercise first. The doctor. A lot of it came from the doctor, plus I don't want to take a whole bunch of pills too, well nobody does.*

Still, at times participants mentioned having difficulty remembering to take medications or attend appointments, suggesting that their drug use or other complexities of their health and social issues interfered with maintaining a routine.

4. Discussion

In this study, we addressed a knowledge gap related to chronic disease self-management among marginalized PWUD. Our approach involved moving beyond a disease-specific perspective to take a holistic, person-centered view of how PWUD self-manage their chronic conditions, highlighting the interplay between managing drug use and other health issues. This distinguishes our work from past research on self-care among PWUD, which has focused on either single health issues (e.g., mental health, chronic pain) or more commonly on drug use or harm reduction only. Furthermore, using the transformative paradigm and a CBPR design to gather the unique experiences of PWUD was critical to ensuring that we emphasized self-managing as a self-defined process, recognizing PWUD's decisive agency and aiming to enhance power and equity for this marginalized group (Kendall et al., 2011). This approach led us to appreciate participants' broad views on health and self-management, which extend beyond any single health condition or any single reason for using a particular strategy (e.g., several referred to "taking care of myself"). Such non-disease-specific views are consistent with the holistic nature of prominent strategies they highlighted (e.g. creative activities) and demonstrate the need to embrace more person-centered and whole-person approaches as a basis for self-care initiatives (Frisch & Rabinowitsch, 2019).

Our findings demonstrate the enormous multimorbidity and diversity of chronic health issues that PWUD experience, most notably various forms of chronic pain. Our findings also highlight the complexity surrounding PWUD's self-management experiences, foremost of which was the use of non-prescribed drugs to self-medicate chronic health issues. However, this was not a simple, linearly beneficial relationship, as participants also expressed how their drug use itself was a chronic health issue and they desired to manage it better. Still, often the most challenging aspect of their drug use was managing the symptoms that resulted when they were unable to consume drugs. For these reasons, it is not surprising that while most participants considered their drug use to be a chronic health issue, they described it differently from their other chronic conditions. While there is quantitative evidence that substance use disorders are more likely to be chronic (Fleury et al., 2016), our qualitative CBPR approach provides a more nuanced understanding of what this means in the daily lives of PWUD. Overall, the relationship between drug use and other conditions was bidirectional, highly complicated, and always changing, with other conditions sometimes leading to worsened or improved drug use, and drug use sometimes worsening or improving other conditions.

Participants highlighted many self-management strategies, with the types of strategies chosen demonstrating the importance of agency in self-management decisions. Self-medication was particularly prominent in their accounts, mainly including the use of opioids, stimulants, and cannabis to mitigate symptoms from mental health conditions, chronic pain, and gastrointestinal or sleep-related issues. The self-medication hypothesis specifies that people use non-prescribed drugs to treat mental health symptoms (Khantzian, 1997). Yet our data highlight that participants used drugs for a larger range of ailments, especially an array of primarily pain-related issues. As other research has found, PWUD may trust their ability to self-medicate more than medical doctors (Smirnova & Owens, 2017) or they may lack access to healthcare and pain medication (Dassieu, Kaboré, Choinière, Arruda, & Roy, 2019b; Voon et al., 2014). In addition, many of the self-management strategies participants described are activities typically classified as harm reduction practices. This corroborates previous work demonstrating the overlap between harm reduction and self-management practices among PWUD (Boucher et al., 2017). In the present study, however, PWUD's harm reduction strategies were greatly driven by the overdose crisis.

Few participants detailed using the most well-recognized self-care strategies such as nutrition and physical activity, topics that are typically a focus in self-management programs (Lorig et al., 2013). Other strategies did map onto common self-management program topics, such as cognitive and behavioral strategies, seeking out healthcare resources, and adhering to healthcare guidance. However, much of the participants' self-management involved strategies that are unlikely to be included or accepted within generic self-management programs, most notably self-medication with non-prescribed drugs, but also harm reduction practices and managing aspects of drug use such as withdrawal. Thus, the self-management needs of PWUD may not conform well to the information promoted in typical chronic disease self-management programs, and self-management supports should ideally be tailored to include the most relevant topics for this population. Still, generic programs often include skill-building activities that focus on improving self-efficacy and involve some tailoring to individuals, aspects which may make them useful for PWUD. Hence, we suggest that if these supports are provided, a peer-led approach would enhance comfort with discussing the issues identified in our study, as peer support is particularly helpful for disadvantaged and stigmatized groups (Sokol & Fisher, 2016). For instance, one qualitative evaluation of a self-management program with people living with HIV highlighted the need to focus more on mutual aid and collectively defining user needs (Kennedy, Rogers, & Crossley, 2007). Furthermore, such supports for PWUD should not be strictly focused on chronic health issues, given the prevalence of acute health issues which may not only take precedence but also be experienced as chronic or become chronic if unaddressed. Additionally, the benefits of creative pursuits for many PWUD speaks to the need to attend to such activities within self-management supports, and perhaps suggests a role for improving access to art therapy and music therapy to support PWUD.

Our results also highlight that self-medicating chronic pain was a major force in perpetuating drug use. While most participants felt well supported for managing their infectious diseases, accessing adequate pain management supports was a clear gap. Substance use and mental health supports were also inadequate. To improve their capacity to self-manage, PWUD need improved access to chronic pain, mental health, and substance use supports. While multidisciplinary care may be the gold standard for these complex health issues, such supports are rarely accessible to socioeconomically marginalized groups. For PWUD, especially those with highly unstable drug use, these services must also be low-threshold – meaning they have taken steps to reduce barriers that obstruct marginalized groups from accessing (e.g., through drop-in or outreach provision, anonymity and non-judgement) (Islam, Topp, Conigrave, & Day, 2013). Furthermore, providing a safe supply of pharmaceutical-grade drugs that meet people's needs is critical as a first-line measure, for numerous reasons. These reasons reflect recent findings from an evaluation of an opioid safe supply program in Vancouver, Canada, including reducing overdose risk, improving health overall but especially management of pain-related issues, and mitigating financial struggles (Ivsins et al., 2020). On the other hand, current opioid agonist therapy options are insufficient to meet the (self-)medication and life-saving needs of many PWUD, especially if living with chronic pain (Dassieu, Kaboré, Choinière, Arruda, & Roy, 2019a), nor are there sufficient approved treatments to address the (self-)medication needs and increasing number of overdose deaths among stimulant users (Fleming, Barker, Ivsins, Vakharia, & McNeil, 2020). Thus, as our participants emphasized, access to a safe supply of both opioids and stimulants should be a priority to support self-management among PWUD, especially recognizing that people in our North American setting are managing within the context of an overdose crisis.

Additionally, the value placed on cannabis as self-medication in our data is deserving of attention, for several reasons. First, cannabis was described as a helpful and versatile self-medication among participants for a breadth of health issues. Second, cannabis was not considered to share the complexity of the other drugs that participants used to self-medicate, in particular the need to manage risks of withdrawal, addiction, and overdose. Third, since cannabis was legalized across Canada relatively recently, there may be greater potential to expand its self-medicating benefits into PWUD's encounters with the healthcare system. In addition to accumulating evidence of cannabis' therapeutic value across many conditions that are common in this population (Babson, Sottile, & Morabito, 2017; Bhattacharyya et al., 2018; Gibson, Hitchcock, Bryan, & Bidwell, 2021; Jensen, Chen, Furnish, & Wallace, 2015), there is also increasing recognition of its harm reduction potential (Lucas, 2017). Evidence suggests cannabis use reduces the use of drugs like opioids and benzodiazepines (Meng et al., 2021; Purcell, Davis, Moolman, & Taylor, 2019). However, the cost of cannabis treatments must also be covered through public drug insurance if socioeconomically marginalized populations are to receive these medical or harm reduction benefits.

Despite several key strengths, including extensive community involvement and a sample showcasing diverse experiences, our study also had a few challenges. First, our sample size was smaller than planned because data collection was interrupted by COVID-19, but we had rich data for each participant thus were able to adjust our analysis focus to ensure the quality of our findings was not hindered. While our sample size was modest and we recommend some caution in interpretation, we found several robust shared patterns with important clinical and theoretical implications, as well as other novel insights that can contribute to hypotheses for further research. Future studies should investigate this topic in other and larger populations and contexts using a variety of methods for further substantiation. Second, even with our community-informed process, the topic was challenging to discuss with participants, resulting in additional time and community engagement for analysis and interpretation. As noted in our results, participants had difficulty focusing on self-management for their chronic health issues and preferred to discuss how they managed their health overall, including their many acute health issues and preventive concerns. However, we recognize that such distinctions are not always easy nor useful to make and believe this is an important consideration for future research. For instance, other self-management studies could either be more explicit about including broad concerns beyond chronic health issues, or impose stricter definitions of terms to facilitate a narrower focus – to determine if these changes lead to new insights. Similarly, given that participants sometimes expressed sentiments indicating they had a wide-ranging perspective on self-care (e.g., including actions like getting a job), future work could also explore various conceptualizations of self-care.

In summary, marginalized PWUD use many self-management strategies to address their chronic health issues and drug use. Chief among these is using non-prescribed drugs to self-medicate their health issues. A host of cognitive and behavioral strategies and creative pursuits are also beneficial, as are seeking out healthcare resources and adhering to healthcare guidance. To 'meet people where they are', especially within the context of the overdose crisis, we recommend providing a safe supply of pharmaceutical-grade drugs to improve the capacity of PWUD to self-manage their health issues. Further, improved access to multidisciplinary pain management, mental health, and substance use treatments are essential, as is access to medical cannabis. We also recommend enhancing opportunities for PWUD to participate in activities that fulfill their creative desires. Existing chronic disease self-management supports are unlikely to fully address the most prominent needs of this population, particularly due to the lack of emphasis on critical topics such as self-medication, harm reduction, and drug use concerns such as withdrawal. Self-management supports for marginalized PWUD should be tailored to include these core needs, while supporting their agency to choose their own self-managing preferences.

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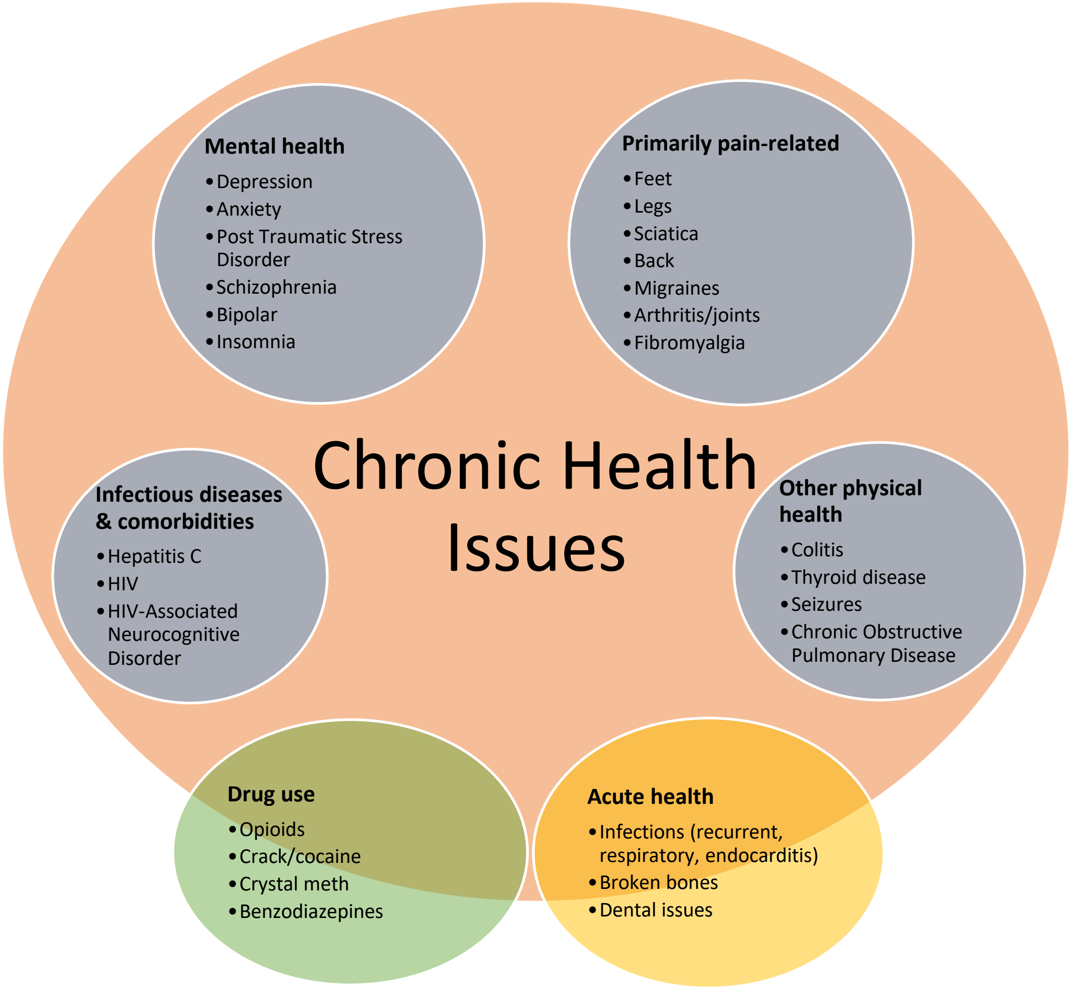
Appendix 1

Supplemental Table 1. Sociodemographic participant characteristics

Characteristic	**Participant responses**
Age (years)	• Mean = 45 (range = 27-70)
Gender identity	• 7 male • 6 female • 2 other (transgender/non-binary)
Sexual identity	• 10 straight/heterosexual • 5 other (gay/bisexual/pansexual)
Self-identified racial/ethnic group*	• 9 White • 2 Indigenous • 2 White/Indigenous • 2 other
Length of time in Canada	• 13 were born in Canada
First language	• 13 English • 1 French • 1 other
Education (highest level completed)	• 5 Some high school • 2 High school graduate/GED • 6 Some college or university • 2 College or university completed
Training	• 10 had received training from employment or volunteer experiences, including those offered through community organizations (e.g. CPR, cultural competence, kit making, other harm reduction/peer work-related skills)
Income source (last 12 months)*	• 8 Ontario Disability Support Program** • 4 Ontario Works** • 2 Canada Pension Plan Disability • 8 jobs (part-time or casual) • 10 family/friends • 4 sex work • 5 dealing • 3 panhandling • 4 selling handmade items • 6 other street-based income
Housing stability***	Housing stability was mixed among participants. While a few indicated they had adequate permanent housing, the majority expressed some issues with unstable housing (ranging from being unsheltered or in emergency shelter, to facing eviction, to living in rooming houses or inadequate social housing).

*Responses to these questions were not mutually exclusive

**Ontario Disability Support Program and Ontario Works refer to receiving monthly disability or income assistance payments, respectively
***While we did not ask about housing stability in the questionnaire, we summarized data collected in the interviews and provided it here as contextual information



Supplemental Figure 1. Summary of types and examples of participants' overall health issues. The categories of 'Drug use' and 'Acute health' are represented in different colors and only partly overlap with the larger circle because participants considered them to be 'Chronic health issues' in some but not all respects.

Chapter 3: Component Article 2

"They're all struggling as well": Social and economic barriers and facilitators to self-managing chronic illness among marginalized people who use drugs

The aim of the study was to investigate the question: What are the barriers and facilitators to self-managing chronic health issues including drug use among marginalized PWUD?

The study was approved by Bruyère Research Institute (M16-19-027) and University of Ottawa (H-10-19-5175) Research Ethics Boards.

Contributions of co-authors: For study 1, Lisa Boucher led the conceptualization, study design, analysis and interpretation, and writing of the two journal articles. Drs. Kendall, Liddy, Leonard, Presseau and MacPherson provided guidance throughout the study, as did the Community Advisory Committee members (Alana Martin, Dave Pineau, Christine Lalonde, Nic Diliso, and Terry Lafleche). Drs. Shoemaker and Fitzgerald also supported conceptualization and analysis. Lisa Boucher wrote the complete first draft of the articles and all authors provided feedback prior to submission.

Published in manuscript form as:

Boucher LM, Shoemaker ES, Liddy C, Leonard L, MacPherson P, Presseau J, Martin A, Pineau D, Lalonde C, Diliso N, Lafleche T, Fitzgerald M, Kendall CE. (2022). "They're all struggling as well": Social and economic barriers and facilitators to self-managing chronic illness among marginalized people who use drugs. *International Journal of Qualitative Studies on Health and Well-being*, 17(1).

The electronic version of this article is the complete one and can be found online at: https://doi.org/10.1080/17482631.2022.2082111

Abstract

Purpose: Self-management is recommended for addressing chronic conditions, and self-management programs improve health behaviours and outcomes. However, social and economic factors have been neglected in self-management research, despite their relevance for marginalized groups. Thus, we aimed to explore barriers and facilitators that influence self-management among socioeconomically marginalized people who use drugs (PWUD).

Methods: Using community-based participatory methods, we developed a qualitative interview guide and conducted peer-led recruitment. Participants were admitted into the study after self-identifying as using non-prescribed drugs, having a chronic health issue, and experiencing socioeconomic marginalization. Data were analyzed using reflexive thematic analysis, taking a relational autonomy lens.

Results: Participants highlighted substantial barriers to managing their health issues, mostly stemming from their social and economic environments, such as unstable housing, low income, lack of supportive social networks, and negative healthcare experiences. Participants also described how their ability to self-manage their chronic conditions benefited from specific aspects of social interactions, including close relationships, community connectedness, and engaging in peer support.

Conclusions: Our findings suggest that structural interventions are needed to support self-management among marginalized PWUD, especially stable housing. Self-management supports for PWUD would benefit from including a range of low-barrier community-based options, peer work opportunities, and advocacy for needs.

1. Introduction

People with low incomes tend to be negatively impacted by additional social determinants of health, which drive health inequalities including heightened morbidity and mortality (Public Health Agency of Canada, 2018). For many people who use drugs (PWUD) illicitly, who often experience socioeconomic marginalization, these poor outcomes are exacerbated by the complexity of their health and social issues (Kreek, 2011; Richardson et al., 2015). In addition to their drug use, common long-term conditions include chronic pain, mental health conditions, and infectious diseases (Dassieu, Kaboré, Choinière, Arruda, & Roy, 2019; Kendall et al., 2017). Many PWUD also identify with multiple marginalized groups, thus often facing intersectional stigma, for example due to racism, heteronormativity, poverty, criminalization, drug use, and stigmatized health issues (Boucher et al., 2017; Logie, James, Tharao, & Loutfy, 2011).

Given evidence that self-management programs improve health outcomes across many chronic conditions, self-management services are growing within health and social care domains (Allegrante, Wells, & Peterson, 2018). Self-management can be defined as "the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with the medical management, role management and emotional management of their conditions" (Adams, Greiner, & Corrigan, 2004). As most chronic illness self-management occurs in people's day-to-day lives, outside of the purview of healthcare, tailoring self-management supports to suit their everyday contexts is an important consideration. Yet, it is unclear whether the current body of self-management support evidence applies equally to marginalized groups, and specifically PWUD. A number of authors have identified gaps in the literature on chronic disease self-management initiatives, in particular a lack of attention to social and economic conditions, which may contribute to lower availability, accessibility, or acceptability of self-management supports among people with socially complex needs (Goodridge et al., 2019; Kennedy, Rogers, & Crossley, 2007; Newbould, Taylor, & Bury, 2006).

While changing individual health behaviours has been the prominent focus of many self-management supports, there is growing emphasis on the need to target the social elements of self-management (e.g., social networks, social capital), especially with attention to socioeconomically marginalized groups (Goodridge et al., 2019; Morris, Kennedy, & Sanders, 2016; Rogers et al., 2011; Tausig, 2013; Vassilev et al., 2013, 2011). For instance, people living with HIV have highlighted social support and stigma as important aspects of their self-management (McDonald, Slavin, Pitts, & Elliott, 2016), yet participating in social activities and roles has been a neglected outcome in self-management research (Packer et al., 2017). To facilitate addressing social needs as well as stigma, peer-led self-management interventions may be most suited to marginalized communities.

Many of these critiques share a concern that current chronic disease self-management initiatives may inadvertently contribute to adverse outcomes for certain populations (Kendall et al., 2011). That is, unless they increase attention to removing barriers for the most marginalized groups experiencing chronic conditions, these initiatives may further disadvantage people who need the most support. Accordingly, the International Framework for Chronic Condition Self-Management Support has identified health equity as one of four priorities for advancing the field, noting that the reach, range, and access of self-management support needs to be expanded (Mills, Brady, Jayanthan, Ziabakhsh, & Sargious, 2016). This framework and other researchers highlight the need to explicitly target self-management programs to disadvantaged groups to avoid exacerbating health inequities (Mills et al., 2016; Packer et al., 2012).

To investigate this largely unexplored topic and determine how interventions may be best tailored for this population, we required an in-depth understanding of current self-management experiences among PWUD. We sought to assess the social and economic factors that promoted or interfered with the capacity for self-management among PWUD by asking the question: *What are the barriers and facilitators to self-managing chronic health issues including drug use among marginalized PWUD?*

2. Theory

One suggestion for addressing some of these critiques has been to incorporate the concept of *relational autonomy* into chronic illness self-management (Ould Brahim, 2019), as has been suggested for other popular approaches to improving healthcare, such as patient-centered care (Ells, Hunt, & Chambers-Evans, 2011), and even specifically to improve mental health services for people with substance use disorders (Lago, Bógus, & Peter, 2020). A relational conception of autonomy contends that “an analysis of the characteristics and capacities of the self cannot be adequately undertaken without attention to the rich and complex social and historical contexts in which agents are embedded” (Mackenzie & Stoljar, 2000), with particular importance placed on analyzing how oppressive social contexts undermine autonomy. This is opposed to the traditional, individual or personal view of autonomy, which “…neglects social and material circumstances and the power relations that impact choice, agency, and selfhood” (Ould Brahim, 2019). Thus, a relational autonomy lens can contribute to addressing challenges that arise from the typical dichotomy between agency and structure in the social sciences, which also tends to characterize discourse on marginalized groups in both policy and academic arenas (Clapham, 2007). That is, the single concept of relational autonomy highlights the intersection between people’s environmental context and their individual behaviour; thus, it can be used to delineate these complex interactions and unify the sets of factors related to structure versus agency into a fuller understanding of phenomena.

Within the self-management domain, Ould Brahim (2019) highlights the critical importance of autonomy along with the limitations of current interventions, including the way that common self-management programs (similar to other initiatives focused on health behaviour change) tend to neglect the pertinent influences of structural and social factors. Thus, this author proposes that a relational view of autonomy can address many of the existing issues within such initiatives through focusing on environmental factors, advocating for systems-level change, and engaging with a ‘patient nexus’ (including consideration of how behaviours are constrained or supported by social relations, especially class). In this study focused on socioeconomically marginalized PWUD, we drew on relational autonomy in conceptualizing our understanding of self-management, as this approach was particularly important given that limited attention to structural factors is likely to disproportionately harm marginalized groups as well as misrepresent their experiences. This approach allowed us to avoid over-emphasizing the influence of internal individual characteristics on behaviour. Rather, we considered the social and economic circumstances and power relations that affect individuals' self-management, and considered social-ecological models and their emphasis on "interdependence between people, their behaviour, and their environment" (Ould Brahim, 2019) in developing our interview guide, codes, and themes.

3. Materials and methods

The Bruyère Research Institute and the University of Ottawa Research Ethics Boards approved this study (numbers M16-19-027 and H-10-19-5175, respectively), which was conducted in Ottawa, Ontario, Canada. In this North American setting, there has been an opioid overdose crisis affecting PWUD for many years. Drug use is criminalized and drug policies have remained mostly punitive, despite increasing recommendations from experts (e.g., researchers, service providers, decision-makers) for decriminalization and safe supply to stem the worsening toxicity of the street drug supply and resulting death toll (Ivsins et al., 2020). Yet, compared to some other countries (especially our closest neighbour, the United States), Canada has well-established public health support for various types of harm reduction initiatives (e.g., needle and syringe programs, supervised consumption services, naloxone distribution). Such progress has typically been attributed to early leadership among drug user activists in Vancouver, British Columbia (e.g., Insite has been open since 2003 and was the first supervised injection facility in North America). Further, Canada made global strides in progressive drug policy by becoming the second country to legalize cannabis recreationally nationwide in 2018. In addition, in our setting there is currently an affordable housing crisis, which was declared locally in the city of Ottawa in January 2020 (Osman, 2020). With respect to welfare policy in our setting, social assistance or disability payments are available from the province of Ontario to eligible individuals, however the amounts provided remain below the poverty line and restrict formal labour force participation. The disability benefits also provide people with prescription drug coverage, and Canada offers universal public health insurance for core services (e.g., emergency or hospital admission, physician visits). Despite all these benefits, among the wider public, non-prescribed drug use remains highly stigmatized, which affects many aspects of life for PWUD, including limiting the accessibility of healthcare (e.g., pain management) and social services (e.g., housing supports).

In this study, we established a community-academic partnership through community-based participatory research (CBPR) (Israel et al., 2010). CBPR emphasizes the meaningful participation of people with lived experience, as well as co-learning and acting for social change (Flicker, 2005), with expert consensus highlighting the importance of engaging community members in self-management initiatives (Mills et al., 2016). Despite the notion that patients are key experts on chronic disease self-management (Lorig, 2002), those who are marginalized are often left out of decision-making that affects them. Thus, we employed a transformative framework to help amplify the voices of this marginalized group and support addressing social inequities (Creswell & Poth, 2018), which is compatible with the focus of CBPR on acknowledging the value of experiential knowledge (Flicker, 2005).

The lead author had experience working with the study population in previous participatory research studies and ensured community members were engaged throughout the study process. There were no conflicts of interest within these working relationships (e.g., the lead author was not a healthcare or social service provider and thus did not have perceived or actual control over participants' access to care). The Community Research Coordinator had lived experience of drug use and socioeconomic marginalization, as did four other community members selected for the Community Advisory Committee (CAC). They were selected for having different levels of past research experience, representing diverse social positions and experiences in common with the study population, and being engaged with community organizations in various capacities. CAC members provided guidance on methods, developed data collection tools, conducted recruitment, supported analysis and interpretation, and strengthened knowledge translation. Members signed confidentiality forms and were compensated for their work.

We developed a semi-structured interview guide through extensive CAC discussions, with focused attention on identifying the most appropriate language for the community. For example, we decided to ask participants plainly what factors influenced how they 'manage' their chronic conditions, and to use the term 'self-care' as it was more familiar to the community than 'self-management'. Questions focused on barriers and facilitators to self-managing chronic conditions, including relevant supports, such as "What makes it harder for you to manage your long-term health issues, including/or your drug use? What makes it easier?" and "What supports or services do you receive to help you manage your chronic health issues?" We also developed a list of prompts to ensure we could explore the relevance of certain factors (e.g., stigma, social networks).

CAC discussions resulted in narrowing the eligibility criteria to focus on participants who self-identified as having: 1) past year and long-term use of non-prescribed drugs (i.e., use of drugs obtained illicitly or prescription drugs not as directed, but not including only cannabis); 2) at least one other chronic health issue; and 3) current financial difficulties. We used the maximum variation purposeful sampling strategy to identify important differences in perspectives (Creswell & Poth, 2018), with the CAC considering relevant factors to include: sex, gender, sexual orientation, age, ethnicity, typical health issues and drug use patterns in the community, typical marginalizing experiences (e.g., housing, sex work, incarceration), and degree of engagement in services.

Our recruitment process was based on a successful street-based, peer-led approach employed in prior qualitative research among this community (Boucher et al., 2017). The CAC identified "hot spot" locations and three different community researchers led recruitment. This process capitalized on community researchers' access to marginalized PWUD while also facilitating introduction and rapport for the lead author with participants. To reduce non-attendance, recruited individuals were mostly scheduled for an interview within a few hours. Given that interested participants had to identify as engaging in stigmatized activities and some of our questions were sensitive, we were careful to assure potential participants that their responses would remain confidential, and we purposely refrained from asking specific details about certain topics (e.g., criminal behaviours or traumatic experiences).

We conducted in-person, one-on-one qualitative interviews and compensated participants CAD 30.00 for their time. Data collection and analysis were iterative, allowing ongoing refinement of the interview guide and recruitment strategy. Four community-based organizations were identified as preferred sites to conduct interviews because many marginalized PWUD frequent them in our setting and find them to be welcoming spaces. Further, these locations were chosen because they contain many supports specifically targeted to this population (including low-barrier, drop-in supports and counseling), thus in the event of a crisis during data collection there would be support available to participants. We also created and provided a list of community resources to interested participants. The lead author conducted all interviews, obtaining prior written informed consent and administering a brief sociodemographic questionnaire subsequently.

Interviews were audio recorded and transcribed verbatim, then transcripts were coded by hand and within NVivo software (QSR International Pty Ltd, 2013). We used reflexive thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2019a; Braun & Clarke, 2020), a qualitative research approach in which both manifest and latent content are considered during data analysis, with patterns and threads identified across the data. Two academic and one community researcher collaborated to conduct coding, with the community researcher also providing cultural interpretation. Codes and themes were then brought to discuss with other academic and community members of our team, with adjustments made to reflect the insights gained. We generated all codes and themes through an inductive approach, rather than identifying any in advance. A focus on data saturation was not conducive to our analysis and instead we applied the concept of information power, which is supported by our focused study aim, theory-guided investigation, and data containing strong quality dialogue (Braun & Clarke, 2019b; Malterud, Siersma, & Guassora, 2016).

We considered trustworthiness criteria to improve rigour and quality in our methods (Guba, 1981). To increase validity, we adopted line-by-line coding and constant comparison (Creswell & Poth, 2018). In addition, we used the following strategies: acknowledged our personal biases and assumptions (e.g., examined social positions and power); collected rich contextual details to facilitate assessing how applicable findings are to other contexts; and used thick quotes to allow readers to make their own judgements (Noble & Smith, 2015; Shenton, 2004). Pseudonyms are used to maintain participant confidentiality.

4. Results

Interviews were an average length of 1 hour and 13 minutes. Our sample included 15 participants with an average age of 45 years (range = 27 to 70), 47% male, 67% heterosexual, and 60% white. In the past year, 93% received either disability or social assistance payments, 53% worked part-time or casual jobs, 67% received some money from family or friends, and 73% obtained street-based income (i.e., sex work, drug dealing, panhandling, selling handmade items, other activities). Further details about the sample characteristics and self-management strategies are reported separately (Boucher et al., 2022), including that most participants considered their drug use to be a chronic health issue. All had extensive experience using stimulants (e.g., crack/cocaine, crystal meth), opioids (e.g., heroin, fentanyl), or both. Participants had many other chronic conditions, including chronic pain, mental health issues, infectious diseases, and other physical health issues. Acute and recurrent health issues were also experienced frequently.

We identified three themes expressing the nature of key barriers and facilitators that influenced how marginalized PWUD were able to self-manage their chronic health issues, including with respect to meeting basic needs, navigating social networks, and accessing healthcare services.

4.1 Difficulty meeting basic needs interfered with managing chronic health issues

Participants described the ways in which limited access to the material means (e.g., shelter, food, transportation) necessary to meet basic needs interfered with their ability to develop or maintain self-management behaviours and routines. When participants experienced unstable housing or inadequate income, they had to spend much time engaged in survival activities, which were sometimes all-consuming and caused further harm to their mental and physical health. Thus, participants were often unable to address less urgent needs, such as their chronic health issues.

4.1.1 Unstable housing meant lacking a foundation for self-management

The most prominent barrier to self-managing health issues mentioned by participants was an unstable housing environment. They experienced stress due to other people in or near their living space (e.g., people staying/living in their room/building; support staff or building managers) or due to the conditions of the housing or shelter (including lack of space, accessibility, or safety), which worsened their health issues, especially mental health and drug use. For instance, Jeremy highlighted how being homeless contributed to increased stimulant drug use and the inability to maintain a healthy sleep pattern: *"We're deprived of sleep always. And when you are able to sleep, it's hard to remain in a very restful state because you're so used to being woken up or have someone out there who's preying on you for something."*

Jeremy further explained how homelessness led to recurring acute health issues and interfered with the ability to manage them well enough to avoid progression to chronic issues:

> *…everyone I know has issues with their feet…you don't often have an opportunity to have the proper foot gear…so many of us end up travelling long distances with you know, wet socks or very cold feet... And staying hygienic, right, is difficult sometimes. So, if you have a tiny scrape or wound, it can get far more, you know, complicated than it normally would.*

Consistency or regularity in daily activities was identified as a key mechanism through which stable housing worked to support self-managing chronic health issues:

> *…having a home, especially, you know, you tend to fall into routines and patterns and go to bed at a certain time or take your medication at a certain time. So, things were much more regimented, and now it's very random. Yeah, so that's really the main thing is that there's no consistency to how I eat or sleep or maintain my health in any way. …Like, in terms of my HIV especially, I'd like to take my medication regularly, see my doctor regularly, have blood work done regularly. (Jeremy)*

Similarly, Cynthia described how finally securing stable housing was the pivotal event that allowed her to start self-managing her chronic health issues: “*But that was one of the first things that allowed me to begin any kind of self-care. …And then I started to be doing things like, you know, I had real problems because of the circulation. I had to go to the chiropody for about a year where they were caring for my feet…”*

Participants also explained how the common experience of losing their housing interfered with progress they were making in managing their health issues: “…*just when I was starting to get up there…and I went down again, you know, just when I was starting to feel really good and strong and I was having a somewhat regular, almost normal routine.” (Rebecca)*

Many participants expressed a strong desire to obtain better housing, with several indicating that it would substantially improve their ability to manage their health issues including drug use, as Rebecca said: “*Oh, I wish I had my own place. I really believe if I had my own place I would be able to quit everything.”* Thus, overall participants spent a lot of effort strategizing how to maintain or improve their housing, limiting how much they could focus on managing chronic health issues.

4.1.2 Insufficient income restricted self-management options

Having inadequate income, and consequently the need to figure out ways to obtain enough income to meet their basic needs, was common among participants and a barrier to managing their health issues. Some participants attributed certain health issues to a lack of access to health services due to their low income. For example, health issues which might have been resolved quickly through obtaining healthcare sometimes developed into long-term concerns, as Jacob described with respect to dental issues: *“I have really bad teeth problems because I'm too broke, I've been broke for awhile. …they're literally like chipped and my root canal fell out…”* Likewise, low income often resulted in a lack of access to transportation, which negatively impacted participants’ health and self-management practices. Because many relied on community services for meals, warmth, hygiene, or other basic needs, they often had to traverse large areas of the city by foot, contributing to ongoing feet problems.

Participants highlighted how finding ways to obtain enough income to meet their needs (including to buy drugs) was critical for managing their health issues, yet the continual searching that this involved consumed much of their time and interfered with other self-management activities. This was especially true among participants who were using drugs more heavily. Many inventive methods were employed, with illegal activities typically a last resort. The need to engage in undesirable activities caused participants stress, which in turn became a barrier to their self-management. For instance, participants who engaged in survival sex work described it as troubling and linked to their drug use: "*Well, it was necessary to do the drugs in order to, you know, do the sex work, in my case at least. And I found that without it, I wasn't really able to, you know, it's not something I could bring myself to do unless I was high. …but it's sort of a vicious cycle." (Jeremy)*

On the other hand, receiving income support (e.g., disability or social assistance, money or items from family or friends) or financial management supports (e.g., direct rent payments) was a facilitator for managing health issues. A few participants also expressed how fortunate they felt in being able to access additional benefits, which for Cynthia made the difference in being able to afford items to address her chronic health issues: "*…I do have compression stockings. …They paid for them because I'm on ODSP but they're like 100 bucks a pair. I would have never been able to afford it."* Similarly, Melissa described how her supports were important for managing unstable drug use:

> *I have a bank account at [a community organization] for the money management. I still need help on different angles and that because it's like it doesn't matter if I don't have the money…it seems like the drugs come my way. ...Now I have to report it back to my worker because now they're doing a budget with me.*

4.2 Navigating social networks presented challenges and opportunities for managing chronic health issues

Participants' social networks had a critical influence on how they managed their health issues, both through their personal social interactions (e.g., with partners, family, friends, peers, and pets) and through engagement with community services. Overall, participants' social environments presented challenges which they had to navigate cautiously to manage their own health issues, especially with respect to mental health and drug use, sometimes leading to self-isolation and lack of connection. Community supports and peer work opportunities helped fill the gaps in PWUD's social networks.

4.2.1 Need to be careful trusting others

Many participants described histories of negative interpersonal experiences, including abuse or betrayal and the loss of loved ones. Such experiences led them to have difficulty trusting others and interfered with forming or keeping close relationships, with most having at least some ongoing conflict with family or friends. Some expressed having a lack of relationships overall: *"I have nobody else in my life but myself." (Melissa)* This lack of social ties harmed participants' health, especially their mental health and drug use. The influence was especially pronounced with respect to being estranged from their children: "*And I have a daughter by the way. … So I haven't seen her in a while, so that's also a different health problem, I guess, mental problem. …It affects everything. …Yeah, like depression hits hard when it hits, especially at times like Christmas." (Michelle)*

Furthermore, participants described interacting with many other marginalized PWUD, which made them wary about trusting or relying on others:

> *…it's so hard to trust people in the scene so, you never really know who's a real friend and who isn't. … It can be difficult to manage those types of relationships and figure out who's, you know, with you because you have access to drugs or because you have something that they want or need. (Jeremy)*

Participants found that these social environments made it hard to avoid using drugs, especially around "cheque day" (i.e., when people receive monthly government income assistance). Some also faced pressure to sell drugs or commit other illegal acts. In housing environments where there were a lot of PWUD (e.g., shelters, rooming houses, some social housing), it was especially difficult to avoid these influences. On the whole, these environmental stressors led to unstable drug use and decreased self-care for health issues. For instance, Anthony noted how being entrenched in the social environment of drug using and selling interfered with managing his health: "*What doesn't make it easier is I have easy access to drugs. …Because it's been a part of my lifestyle for awhile so any drug I want I can easily get my hands on and so that does not help my health issues."*

To manage these social challenges, some participants chose to have few close relationships. For instance, some felt the need to isolate when they were using drugs or to hide their drug use from specific others: *"But good friends I don't access them enough, you know like I…I don't want them to know what's really going on." (William)* While this lack of connection was at times upsetting, at other times it helped participants focus on managing their own health issues. For instance, especially among women participants, intimate relationships could present challenges to managing health. As Michelle noted, her current relationship exacerbated her mental health issues and drug use: *"So like that's a big stressor and that's one of the main reasons I use a lot more than usual."* Some women reported not being interested in romantic relationships because they were managing better on their own. Melissa, who had experienced domestic abuse and serious mental health issues, expressed a strong desire to abstain from such intimacy: "*I'm finding that I'm pretty stable now because I don't have no boyfriend or no girlfriend… No. I don't want no relationships."*

4.2.2 Obtaining social supports to meet emotional and practical needs

Most participants reported having at least some social support that helped with managing their long-term mental and physical health issues. Having either a few close relationships or a larger social network contributed to improved self-management, as did being connected to one's community in general. While the main types of social supports participants described were emotional ones, they also received practical supports from others, including financial contributions, access to resources or items, and information or assistance with completing tasks, although such supports were comparatively rare.

Among participants who had them, positive romantic partners were another source of support in managing their health issues, especially among men in our sample. Several described having deeply supportive significant others:

> *Anything I ask her to do she does. She goes and gets the bandages for my legs. …I don't know too many of the resources. Like my girl takes care of all that stuff and I got a pretty bad memory too so. (Brian)*

Likewise, as Jacob explained, feeling that someone truly cared helped him use drugs in less detrimental ways, while also motivating him to improve basic self-management behaviours such as nutrition:

> *…since [my girlfriend]'s come into my life I haven't been fucked up with opioids to the point where I'm like, you know, bumping into shit, and with benzos I haven't been blacked out... now that I have someone that like genuinely cares about me and isn't just trying to get something out of me, you know, it feels really good… Me and [my girlfriend] both have only started to eat since we've been together because we're like – reasons to care for yourself is for the other person, right? So like I've been eating a lot more since – I used to eat basically like the cheapest things…*

Similarly, some participants described an immense positive influence on their mental health and self-care activities from close friendships. As Rebecca described, her friend provided both emotional and practical support:

> *But I finally found somebody who I can trust, and she's really helped me a lot, and I feel mentally a lot stronger now… And she's really creative, and she's very warm and everything… She really encourages me, yeah, to do all the things I want to do, and she really gets me started...*

In contrast, other participants' most critical social supports stemmed from being well-engaged with certain services in the community, including with community workers (e.g., case managers, mental health workers) as well as entire organizations that provided a plethora of support options. For instance, participants highlighted how specific service providers had a huge impact on their progress toward improved self-care:

> *Like she – people are so empathetic and understanding and supportive and it's – those things are essential because even if you want to make change in your life…you can't see a way there until somebody starts saying here, come with me, I'll put you on that path, you know, I'll nudge you over here, I'll lift you up here or I'll drive you here or, you know, get you involved in this… (Cynthia)*

When asked about whether they had community support or felt like they were part of a community, participants often interpreted this as referring to community organizations that they engaged with and which helped them in a multitude of ways: *"…it's like my second home, I'm here so often." (Scott)* Low-barrier, one-stop-shop style supports were particularly helpful. Several participants also highlighted how their preferred community organizations encouraged their input on how to best offer supports. Moreover, feeling connected to community motivated participants to deal with their health issues in improved ways, as in this example in which engaging in community activities directly helped Eric improve his drug use:

> *It was a pot luck and drumming and Aboriginal gathering. I chose to go to that because I didn't want to use that day, because it was cheque day and I had a pocketful of money and I'm like, well I want to do something different today. And I did. I really enjoyed it. It was quite fun. It didn't make me think about using or anything, a positive group of people and we had a great time.*

Similarly, when asked what helped her to cope with her health issues, Michelle described how panhandling made her feel more connected to the broader community: "*I go panning. I'm a people person, I like people. …and it helps me talk to somebody who I don't know and just talk to say hi, and they stop and talk to me and it makes me feel like you're more wanted, I guess in a way, and you're not being judged by certain people."*

Participants also expressed the importance of receiving peer support through community organizations. They described preferences for different types, with some preferring one-on-one and others group supports, as well as specific or innovative ideas for how it should be offered: "*I wish there was more – like a mentorship program... Kind of like what AA people, in AA have, you know? … But like something more for opioid users, you know some kind of people who have been through that and have overcome it." (Rebecca)*

Nevertheless, some participants were connected to few or no community supports, despite recognizing the value of such engagement and desiring to pursue more connectedness.

4.2.3 Supporting peers and others

In addition to the benefits of receiving social support from others including their peers, participants highlighted how much they benefited from providing support to others. This included working in formal peer worker roles, as well as informal support they often provided for friends, family, pets, and acquaintances in the community. Engaging in such helping activities enhanced participants' social networks and sense of community connectedness, reducing isolation and increasing their desire or capacity to engage in self-care and continue caring for others. While participants engaged in many different forms of helping, most desired more paid peer work opportunities, given that their precarious financial situations made it challenging to engage in unpaid activities.

On the whole, participants emphasized the powerful nature of peer support among PWUD, including how a positive feedback loop occurred through helping one's peers, as Jacob described with respect to his volunteer peer support role:

> *So it's like a user base kind of, we're all helping the community, trying to like help each other, right? …that's been the best support system just because it's about drugs and addiction and I can talk to them and they understand. …the best form of recovery and the thing that works, and has been proven to work the best, is addicts helping other addicts.*

Michelle expressed that being involved in creating and providing formal peer supports made her feel accomplished, which motivated her to take better care of herself: *"So women had a place to drop in between that time out of the cold in the winter especially. So yeah, we did that for, I did that for a year and a half. And I was one of the ones that initiated it. So it felt good. So stuff like that it makes me want to, you know, do better."*

However, while many participants were generous in trying to help other people who were also struggling, the added stress from doing so often risked their own self-management: *"I* *used to take the odd person off the streets, take them home with me… With their mental health stable and my mental health stable and that, you just can't deal with it. …Because you're only going to bring yourself down. So now I don't bring nobody home..." (Melissa)* While sometimes PWUD were taken advantage of when they tried to help others, on other occasions their mental health was harmed when their efforts to help others did not succeed: *"So I promised myself no more of that, because they just stressed me out, so yeah. …I get stressed out because I can't help them. …I don't want to feel any worse than I do about not being able to help my friends." (Mark)* Thus, many participants came to the conclusion that they needed to prioritize their own self-care before they could help others: "*I used to always be like how I showed somebody I cared for them was to do everything for them and then I took a backseat myself and anything to do with my own life took a backseat. …but I have no problem prioritizing myself now. ...So I feel good about that…" (Cynthia)*

Similarly, when asked whether his peer group was supportive, Jeremy provided a few reasons why it was challenging to maintain mutual support amongst marginalized PWUD:

> *As much as they can be, but they're all struggling as well, right? They're all dealing with their own emotional and mental fragility, you know, so it's hard to be a real support to each other. …you're not always able to be in contact with them because we don't necessarily have phones. …getting to a computer to use email is difficult. …So, communication is really tricky when you're living this way. …And knowing where someone might be at any given time is almost impossible.*

Furthermore, a participant who was an employed peer worker emphasized why it is important to increase the extent of paid peer positions, rather than expecting marginalized PWUD to rely solely on support from their social networks, which largely consist of other people who are struggling:

> *Because I see many people, and especially those people that are in crisis that I'm helping…completely alone in life, like most people don't have anybody but other badly bent people. …because most people even if they have friends that are in the same boat as them they're not in a position to really do much to help. (Cynthia)*

4.3 Negative experiences accessing healthcare services limited chronic illness self-management support options

Participants described how they needed to access many different health and social care services to manage their chronic health issues. While community supports were typically helpful, more traditional healthcare services presented problems for PWUD. Participants often highlighted unmet healthcare needs due to inadequate access or negative experiences. Access issues related mainly to socioeconomic and systemic healthcare conditions. Lack of access to primary care and specialist providers and to certain medications was noted, as well as lack of or misinformation, difficulty getting to services (e.g., proximity, transportation, weather), and a lack of low-barrier services to address their multiple healthcare needs. Participants with complex health issues reported finding it hard to obtain a regular doctor:

> *Every time I call that Telehealth thing they call me back with an appointment with a doctor and then they look at the list of the medication I'm on and they turn around and call back a day or two before saying that they can't help me and they'll see if they can find me another doctor. It's been going on for two years.* (Brian)

While many of participants' negative interactions resulted from discrimination, some may have been related to other systemic issues, such as inadequate training or resources. For example, participants who injected drugs experienced challenges in having blood taken because it took providers many tries to find a vein. Many participants also described unpleasant experiences with psychiatrists or psychiatric medications. While several had positive experiences with counselling, others were not comfortable with it and some even found it interfered with managing their mental health issues, as in Amy's example:

> *…it's dug up more pain than I can manage… Social workers, psychiatrist, counsellor, psychologists... Just picking away and thinking they're doing more good, but it's actually making the problems come out a lot more, a lot faster, and a lot harder. …and when you're talking about this stuff, they're only available when they're available, but when they open wounds, they can't just stitch them up whenever they can. …You leave the wounds stuck open, then I'm open and I'm vulnerable, and I have no idea what to do with myself. Do I go get more help or do I feel like killing myself or what?*

Overall, the stigmatization of PWUD was the greatest barrier participants reported in accessing healthcare to support managing their health issues. Given lack of primary care access, participants often had to seek care in hospitals, which resulted in highly negative experiences that led to future healthcare avoidance: *"As soon as they see my history they are so judgemental and so rude and just cold and mean. That's the worst place. Even if I'm really sick it takes a lot [to go there]." (Rebecca)*

However, while many participants encountered difficulties with advocating for themselves, a few highlighted the importance of advocacy as a facilitator for self-management in interactions with healthcare providers. Cynthia described her need to self-advocate to get support for managing a chronic health issue during an encounter in which she felt she was stigmatized against based on her drug use:

> *I didn't feel I had a lot of support from my [specialist]. Like anything I learned about my condition I did not learn from her and every time I asked for help or asked to be seen or whatever, like I mean she really literally was not doing anything. …And when I went back to her I said, you know, the first day I met you and described my history of addiction I saw a look pass over your face that I've seen many times, that has to do with those biases and stigmatism and I said I don't know if you're aware of it. But anyways meanwhile I'm like needing somebody, I don't know if we're going to go further together on this or if you're going to refer me to somebody but I am now putting you on notice…*

5. Discussion

In this study, we attended to several important gaps in the chronic disease self-management literature, facilitated by our relational autonomy approach to self-management (Ould Brahim, 2019). In light of the critiques of self-management initiatives for failure to consider the social embeddedness, access to economic resources, and power dynamics that shape people's lived realities, we investigated barriers and facilitators that influence the ability of marginalized PWUD to self-manage their chronic health issues. Our findings demonstrate how challenging social and economic environments constrain self-management, as participants experienced many more barriers than facilitators, which all correspond to well-known social determinants of health.

The most persistent impediment to managing chronic illness occurred when participants did not have their most basic needs met. Stable housing was foundational to developing and maintaining self-management practices in PWUD's daily lives, as many negative housing and shelter-related experiences interfered with managing their health issues, including by worsening their drug use. Most expressed that more stable housing would allow them to improve how they manage their health issues. They spent substantial effort looking for better housing or maintaining current housing, which also interfered with prioritizing health issues. The prominence of housing concerns in this study was not surprising and highlights the importance of providing permanent supportive housing to facilitate stability as a basis for self-management, adding to evidence for Housing First among PWUD (Palepu, Patterson, Moniruzzaman, Frankish, & Somers, 2013). Further, participants discussed how they could not focus on managing long-term health issues due to inadequate income and time spent finding various ways to obtain enough income to meet their needs. Together, both unstable housing and low income prevented PWUD from developing consistency in their daily routine, which was critical for their chronic disease self-management. In addition, these socioeconomic challenges contributed to more acute health issues which necessarily took precedence over chronic health issues, and sometimes even became chronic when unaddressed. This relates to participants' frequent use of emergency healthcare services versus primary care services, corroborating previous findings with this population (Kendall et al., 2020; Kendall et al., 2017).

Another critical theme was social interactions, which either hindered or supported participants' chronic disease self-management. This is unsurprising, given the influence social networks have on self-management (Vassilev et al., 2011). Marginalized PWUD must navigate challenging social environments that include many other PWUD and people with low socioeconomic status. Participants often expressed difficulty trusting others and chose to isolate themselves to avoid relying on others. Such choices typically related to their past negative social interactions, including traumatic experiences. On the other hand, some participants described receiving immense emotional support from romantic partners or friends with whom they had formed close relationships. Participants were extremely grateful when they received this high level of support, expressing how it was rare in the context of their lives. In some cases, professional community workers provided emotional support that filled gaps for participants who had very limited or no close personal relationships, and participants were similarly grateful when this occurred. Some participants received practical supports as well from family and friends or workers, but this was less prominent. Finally, participants also described reciprocal benefits from peer support and strong desires to help their peers and others, often attempting to do so informally until it became too difficult to manage their own issues. The scarcity of resources and complex needs of other people in the lives of marginalized PWUD demonstrates the critical detriment of a low-resourced social network (Tausig, 2013). Thus, it is not surprising that many participants also expressed that the potential to work in paid peer support positions would resolve many issues they encountered, allowing them to help both others and themselves, as research on low-barrier employment opportunities has found (Penn, Strike, & Mukkath, 2016). Those in formal peer support roles further expressed the benefits for their own health issues, also corroborating previous research (Watson, 2017).

These findings add to the literature on the importance of social networks in self-management, and our study meets the call of these authors to explore the generic ideas among specific populations and contexts. While people with chronic conditions tend to get most of their social support from close family (e.g., adult children and spouses), many participants in our study did not have these types of relationships (Vassilev et al., 2013). Our findings appear to suggest a critical lack of strong ties and a predominance of weak ties (although some participants lacked even weak ties), and weak ties may not be as helpful for chronic illness management as they are in other areas of people’s lives (Morris et al., 2016). Further, our findings around PWUD’s positive emphasis on peer support and low-barrier services, along with their negative healthcare experiences, highlights potential benefits of shifting the emphasis to self-care supports outside of formal healthcare, aligning with previous findings (Rogers et al., 2011). However, as evidenced by our participants’ experiences, social networks and communities must be supported and resourced to do this work, specifically among PWUD and other marginalized groups where many people are similarly suffering.

Finally, while most participants highlighted benefiting from low-barrier community services, we found some evidence that PWUD's challenges in accessing healthcare services interfered with their chronic disease self-management. In addition to typical barriers to healthcare access, such as transportation, participants faced extensive stigma based on their drug use, which is well-documented in the literature (Biancarelli et al., 2019; Paquette, Syvertsen, & Pollini, 2018). For instance, participants felt discriminated against by doctors when they did not receive adequate pain medication. This is in line with recent research among PWUD with chronic pain (Dassieu et al., 2019), highlighting how common practices of prioritizing substance use in clinical care for PWUD can lead to their other health issues being interpreted through a substance use lens, leading to reduced access to other care. Further, PWUD's negative past experiences with healthcare services made them less likely to trust providers and more likely to avoid them in the future, as other studies have found (Biancarelli et al., 2019; Paquette et al., 2018). Mistrust of the healthcare system among socially complex patients has also been specifically shown to discourage participation in self-management programs provided through said system, likely because such patients expect to feel judged or powerless (Goodridge et al., 2019). Given that seeking care is itself a self-care action, it needs to be encouraged by reducing the access barriers that marginalized PWUD face, such as stigma (Lago et al., 2020). While some PWUD attempt to counter healthcare stigma through self-advocacy, this is unlikely to be either possible or effective for most marginalized people given their low-power social status. Thus, an essential part of community workers' (including peers') roles may be providing advocacy support. Healthcare providers need to consider PWUD's relational autonomy as a key part of delivering patient-centered care, recognizing the structural factors that limit their capacity to self-manage and using this conceptualization to better support their autonomy and thus self-management (Ells et al., 2011; Ould Brahim, 2019). Specialized training may be required to enhance tailored responses for this population.

All three themes are intricately interconnected and demonstrate how substantial social and economic barriers overpower the limited facilitators or supports participants accessed in their attempts to self-manage health issues. Overall, the environmental constraints that participants outlined demonstrate a great need for structural interventions that address resource inequities to support chronic disease self-management among marginalized PWUD. Moreover, our findings align with four identified types of resources that social networks can provide, namely: “social support, social influence, social engagement and attachment, and access to resources and material goods” (Berkman, Glass, Brissette, & Seeman, 2000; Tausig, 2013). As Tausig (2013) emphasizes: “It is precisely these resources that determine the quality of “self”-management of chronic illness”.

Our findings also highlight some potential solutions for improving the conditions for self-management among this population. Supporting peer leadership is imperative for self-management initiatives among marginalized PWUD, especially to address pervasive anti-drug stigma as well as other socioeconomic concerns. Further, our findings indicate that group-based self-management supports could benefit from selecting participants who share similar experiences to reduce the likelihood of stigmatizing interactions. In addition, the predominant influence of social interactions, demonstrated across all three themes, points to the importance of measuring these types of outcomes (e.g., social support, social capital, social roles, stigma) to assess the utility of self-management supports, as these have been identified as essential but neglected outcomes among other populations with chronic conditions (McDonald et al., 2016; Packer et al., 2017). Common goals of long-term condition management initiatives tend to centre on biomedical and health behavioural outcomes, thus may not reflect patients’ everyday lived realities and priorities, especially among marginalized groups. Our findings highlight the need for current public health self-management initiatives that focus more on social and economic contexts, supporting the use of a relational autonomy lens and enhanced attention to health inequities.

The primary strength of this research was the meaningful community engagement achieved through our commitment to participatory methods, which helped to break down the power imbalance that marginalized groups experience and facilitated the smooth conduct of study activities. For instance, we did not experience difficulties in recruitment, despite the need for participants to identify as people who engage in highly stigmatized activities such as drug use. Similarly, despite purposely avoiding direct questions about traumatic experiences, many participants chose to share details on such sensitive topics. We attribute this success to the skilled community researchers who were able to quickly establish trust and lend their credibility to the academic interviewer, resulting in a rich dataset that provided new insights into the oft-hidden lifeworld of marginalized PWUD. Further, the community researchers provided essential support to qualitative analysis and interpretation, especially through sharing their specific local and cultural knowledge, which contextualized and contributed to making sense of the data. However, it is also important to recognize the need to dedicate sufficient additional time and maintain flexibility to ensure that community engagement is truly meaningful, especially with respect to community participation in the analysis process, which is often the least common stage of a research study to involve community members (Flicker & Nixon, 2015).

As a consideration for future research, we note that discourse around participants' life course came up frequently and clearly related to their social and economic resources as well as self-management practices. However, our analysis focused on the present, so fully exploring such connections was out of our scope. We suggest that future self-management research with PWUD or other marginalized groups may benefit from explicitly adopting a life course framework. In addition, given the need for complex systems-level change to support self-management among this population, we suggest future research assess the barriers and facilitators to such change.

6. Conclusions

The marginalized PWUD who participated in this study were considerably constrained with respect to chronic disease self-management due to complex challenges in their social and economic environments. Most prominently, they needed to prioritize attending to unstable housing, low income, lack of supportive social networks, and negative healthcare experiences, highlighting the need for structural interventions to support their self-management. Yet, they also sometimes benefited from specific aspects of social interactions, such as close relationships, community connectedness, and helping others. We recommend that chronic illness self-management initiatives embrace a relational autonomy approach to facilitate understanding the experiences of marginalized PWUD and other marginalized groups, so as to ensure addressing the constraints of their social networks, economic circumstances, and power relations. We suggest self-management supports for marginalized PWUD should include many low-barrier community-based options, peer work or mutual support opportunities, and advocacy for needs including systems-level change.

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Chapter 4: Component Article 3

“They have their security, we have our community”: Mutual support among people experiencing homelessness in encampments in Toronto during the COVID-19 pandemic

The objective of the study was to explore the question: How did mutual support occur among people experiencing homelessness within the social context of encampments during the COVID-19 pandemic?

The Unity Health Toronto Research Ethics Board (#21-035) and the University of Ottawa Research Ethics Board (#H-03-21-6715) approved this study.

Contributions of co-authors: For study 2, Lisa Boucher led conceptualization for the specific research question included in this dissertation, as well as leading the analysis, interpretation, and writing of the journal article. The broader study design process was co-led by Lisa Boucher, Zoë Dodd, and Dr. Young, with support from Drs. Bayoumi and Firestone. Dr. Kendall supported conceptualization of the research question and Abeera Shahid helped with analysis. Lisa Boucher wrote the complete first draft of the article and all authors provided feedback prior to submission.

Published in manuscript form as:

Boucher LM, Dodd Z, Young S, Shahid A, Bayoumi A, Firestone M, Kendall CE. (2022). “They have their security, we have our community”: Mutual support among people experiencing homelessness in encampments in Toronto during the COVID-19 pandemic. *SSM-Qualitative Research in Health*, 100163.

The electronic version of this article is the complete one and can be found online at: https://doi.org/10.1016/j.ssmqr.2022.100163

Abstract

Unaffordable housing is a growing crisis in Canada, exacerbated by the COVID-19 pandemic, yet perspectives of people living outdoors in encampments have primarily gone unheard. We conducted qualitative interviews with encampment residents to explore how mutual support occurred within the social context of encampments. We found that mutually supportive interactions helped residents meet basic survival needs, as well as health and social needs, and reduced common health and safety risks related to homelessness. The homelessness sector should acknowledge that encampment residents form their own positive communities, and ensure policies and services do not isolate people from these beneficial social connections.

1. Introduction

Unaffordable housing is a growing crisis in Canada, resulting in more people living in precarious housing situations or without a home. People experiencing homelessness often face complex health and social issues, including high rates of physical health conditions, mental health conditions, and substance use (Howells et al., 2021). Other aspects of marginalization are also associated with homelessness, including: being Indigenous, Black, or another racialized identity; identifying as 2SLGBTQ+; having experience of criminalization; and living with a disability (Employment and Social Development Canada, 2019; Farha & Schwan, 2020). Further, the housing crisis and the overdose crisis have intersected for years, and, since 2020, they have overlapped with the COVID-19 pandemic. Since the pandemic began, people experiencing homelessness are at high risk for COVID-19 infection, subsequent complications including hospitalization and death (Richard et al., 2021), and opioid-related overdose (Gomes et al., 2021).

Central to the experience of homelessness is being socially excluded and considered an "Other" by mainstream society (Clapham, 2007; Dej, 2020; Sylvestre, 2013). People sleeping on the street are often considered the epitome of this exclusion (Clapham, 2007). People experiencing homelessness often face difficult social environments, including small social support networks with limited or negative social capital and feelings of social isolation and loneliness (Hawkins & Abrams, 2007; Rokach, 2005). They face widespread societal stigmatization and discrimination and are often put in the position of proving their "deservingness" to receive supports through the homelessness sector (Dej, 2020). For example, groups typically considered more deserving include children and women victimized by violence, followed by individuals identifying as severely ill but also complying with treatment program requirements, whereas individuals who are not working or who continue to use drugs are often considered less deserving (Clapham, 2007; Dej, 2020; Doberstein & Smith, 2019; Rosenthal, 2000). Still, all people experiencing homelessness generally must demonstrate their willingness to take responsibility for their circumstances to be considered "redeemable" and thus deserving of support (Dej, 2020).

A few studies have shown that people experiencing homelessness support one another, both informally and through formal peer support initiatives (Dej, 2020; Green, Mason, & Ollerenshaw, 2004; Guirguis-Younger, McNeil, & Hwang, 2014). Peer support initiatives have also been shown to help other groups experiencing marginalization, such as people with mental health issues or who use substances (Batchelder et al., 2017; Boyce, Munn-Giddings, & Secker, 2018; Deering et al., 2009), people living with HIV (Roth et al., 2012), the isolated elderly (Pahk & Baek, 2021), and individuals with low health literacy, low socioeconomic status, or other disadvantages (Sokol & Fisher, 2016). Yet there is less research on informal peer support networks, including limited investigation of their mutuality.

Among people experiencing homelessness, those who are "unsheltered" or "rough sleepers" – which includes people "staying in places that are not designed for or fit for human habitation" (Gaetz et al., 2012) – tend to experience worse outcomes, including morbidity and mortality (Howells et al., 2021; Montgomery, Szymkowiak, Marcus, Howard, & Culhane, 2016). One of the more visible manifestations of unsheltered homelessness is "encampments" or "tent cities", which typically involve multiple people setting up tents or makeshift structures in close proximity to each other on public or private land, thus experiencing some aspects of homelessness together. Encampments often form without official authorization and thus violate local bylaws (e.g., no camping in parks), although some jurisdictions have created mechanisms to formally sanction encampments (Cohen, Yetvin, & Khadduri, 2019). In Canada, these bylaws have engaged significant Charter litigation and human rights analysis, with case law on the subject often invoking section 7 of the Canadian Charter of Rights and Freedoms – that is, the right to "life, liberty and security of the person" – which has provided some protection against forced evictions of encampment residents (Farha & Schwan, 2020). However, the common enforcement of these bylaws has continued to harm encampment residents in Canada and violate international human rights law (Farha & Schwan, 2020).

While encampments have been formed by people experiencing homelessness in many regions across North America, there is little research on how encampments, and communities' responses to them, affect the health and well-being of encampment residents, especially in Canadian settings (Cohen et al., 2019; Farha & Schwan, 2020; Young, Abbott, & Goebel, 2017).

One study interviewed 12 residents of a tent city in Victoria, British Columbia, and found that while residents described negative experiences with services such as shelters and negative reactions from some in the wider community, they experienced a positive sense of community in the encampment (Young et al., 2017). A report written by scholars at the Seattle University School of Law in the United States also proposed that encampments may provide people experiencing homelessness with improved safety and security, community, autonomy, stability, and visibility, compared with other shelter options (Junejo, Skinner, & Rankin, 2016).

The number and visibility of encampments in Canada has increased since the beginning of the COVID-19 pandemic, in part due to concerns about the risk of contracting COVID-19 in congregate shelter settings (Canadian Press, 2020; Fox, 2020). In Toronto, the shelter system was already overburdened yet had to further reduce capacity to meet public health guidelines for physical distancing (Neufeld, 2022). Encampments in the downtown area became very large and there was a vast community outreach response to support the residents, including through the formation of grassroots groups. For instance, the Encampment Support Network was a volunteer-run group that formed shortly after the start of the pandemic by a collection of neighbours and community members who wanted to help meet encampment residents' basic needs, such as by providing tents, blankets, clothing, snacks, and miscellaneous items, as well as engaging in advocacy for improved housing options (https://www.encampmentsupportnetwork.com/). Another supportive initiative was developed by a local carpenter who built Tiny Shelters for encampment residents (https://www.torontotinyshelter.org/), while Toronto Indigenous Harm Reduction formed to provide cultural care among many other supports for Indigenous encampment residents (https://www.torontoindigenoushr.com/). Municipal government workers still attempted to evict encampment residents, as was common practice in prior years (FactCheckToronto, 2021), though they faced increased community resistance. However, an injunction filed by encampment residents and allied organizations during the COVID-19 pandemic to have the City of Toronto cease enforcing the bylaw that enables encampment evictions was rejected by the Ontario Superior Court of Justice in October 2020 (*Black et al. v. City of Toronto*, 2020). Thus, overall, the pandemic shifted typical social dynamics among people experiencing unsheltered homelessness, providing an opportunity to explore the influence of the encampment context on residents' day-to-day lives. Specifically, we asked the research question: *How did mutual support occur among people experiencing homelessness within the social context of encampments during the COVID-19 pandemic?*

2. Theory

We applied concepts of relational autonomy and mutual support to analyze and interpret our data. A relational conception of autonomy involves "...attention to the rich and complex social and historical contexts in which agents are embedded" (Mackenzie & Stoljar, 2000) and is particularly relevant for people experiencing homelessness because their lives are often constrained by low socioeconomic resources and the need to conform to rigid standards to obtain services. Relational autonomy highlights how people's agency cannot be understood without considering their interdependence with other people and environments, thus we incorporated this concept into our analysis by situating encampment residents' mutually supportive actions within their social environment (e.g., through comparing features of the encampment social context versus other contexts they faced). Given that discourse on homelessness and social exclusion has often focused on either structure or agency (Clapham, 2007), a relational autonomy lens facilitates integrating both for a fuller understanding.

While many terms have been used to express similar ideas (e.g., mutual aid, self-help groups, peer support, mutual care), mutual support can be defined as "...peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions" (Katz & Bender, 1976; Loat, 2011). Mutual support can also occur informally between individuals, rather than requiring a formalized group, but it is distinguished from generic social support due to the added element that all parties share similar challenges (Loat, 2011; Pistrang, Barker, & Humphreys, 2008). The literature on social support refers to three key types of interactions as supportive – informational (advice or guidance), emotional (caring or concern), and instrumental (sharing material goods) (Hogan, Linden, & Najarian, 2002) – which may vary in importance by context. Concepts such as informal caregiving or peer support share similarities with mutual support but often label one person as the "helper" and the other as the "helped" (Riessman, 1965). Though the literature also shows that the act of helping others accrues benefits to the people designated as helpers (Batchelder et al., 2017; Embuldeniya et al., 2013; Riessman, 1965), support systems within the everyday social interactions of people experiencing homelessness may operate more reciprocally. Mutual support is also closely aligned with relational autonomy, in that engaging in mutual support may be considered an act of exercising autonomy in a relational way, as well as a way in which marginalized people actively resist their isolating social environments.

We also applied the transformative paradigm to acknowledge power issues and cultural complexity, to centre and amplify marginalized people's voices, and to promote social justice and human rights (Mertens, 2007). In practice, this entailed community leadership and continual conversation with community representatives to facilitate attending to these issues appropriately in study conduct and data interpretation, as well as focusing knowledge translation on achieving social change. Our conceptualization of marginalization was also informed by intersectionality theory, which posits that experiences are shaped by intersections of different social locations (e.g., gender, ethnicity, class, age, disability, sexual orientation), involving power structures, processes of oppression and privilege, and sociohistorical contexts (Bowleg, 2012; Grace, 2014; Hankivsky, 2014; Hunting, 2014; Katz, Hardy, Firestone, Lofters, & Morton-Ninomiya, 2019). Intersectionality-informed qualitative research is highly compatible with the transformative framework and community-based research, especially among stigmatized and socially excluded groups, because all these approaches emphasize the need to attend to power and other issues of context and complexity. This led to design choices such as selecting a diverse sample and including questions about barriers (e.g., discrimination) in our interview guide.

3. Material and methods

This study was conducted in Toronto, Canada, as part of a larger study exploring marginalization during the COVID-19 pandemic. We employed community-based research methods, including community leadership and the involvement of various stakeholders throughout the study, from design to knowledge translation. To inform study design, we first conducted a literature review and created a logic model with the help of representatives from outreach volunteer groups or community-based organizations (Abdi & Mensah, 2016). The logic model outlined the outreach resources and activities that supported encampment residents, as well as the intended outcomes which included community connectedness. We then designed a convergent parallel mixed methods study to explore multi-stakeholder perspectives on the encampment environment and the outreach supports provided in encampments (Craig et al., 2008; Creswell & Clark, 2011; Mertens & Wilson, 2019). The study was led by one PhD candidate, one MD and PhD student, and one Master's-educated community researcher with lived experience. All three co-leads had extensive experience working with multiply marginalized groups in prior community-based research or service provision, especially among people who use drugs.

Informed by the literature review and logic model, we developed a semi-structured interview guide to explore wide-ranging experiences among encampment residents, including those related to encampment living, COVID-19, health and substance use, outreach supports, and shelter or housing supports. Of most relevance to this article, we asked participants to describe their interactions with encampment residents, including their typical daily experiences, roles, and conflicts within encampments, as well as interactions with people external to the encampments (e.g., outreach workers and volunteers, neighbours or other community members), and contextualization of these experiences via comparison to other shelter or housing. We also interviewed outreach workers and volunteers, but their data are not included in this article. Further, we conducted a survey but only the demographic data are presented in this article, as the other survey questions pertained to topics that are less relevant to this specific research question.

We recruited from six key encampment locations in Toronto, chosen because of their prominence in the downtown area and larger sizes, as well as their proximity or distance to various types of community services (e.g., respite, supervised consumption site), and other characteristics that led them to differ, such as including residents with diverse or similar identity factors. While the number of encampments was constantly in flux, there were many more encampments across Toronto. We used convenience and snowball sampling to recruit encampment residents for surveys first, then selected a purposeful sample for the interviews based on responses to the survey questions (especially demographics), using the strategy of maximum variation (Palinkas et al., 2015). Our goals were to capture a wide range of perspectives and housing or shelter experiences, and to represent diverse and multiple marginalized identities, including race, gender, 2SLGBTQ+, and age. Current or former residents of any Toronto encampment during the pandemic were eligible; we included former residents to obtain the perspectives of people who had moved into shelter or housing. The study team did not have prior relationships with participants; instead, recruitment relied on assistance from community groups who had existing relationships with encampment residents and introduced the research staff. Data was collected within the encampments in locations separate from other people so that the conversations would not be overheard. No participants selected for interviews dropped out or refused to participate.

Participants were compensated $15 CAD for surveys and $40 CAD for interviews. All interviews were one-on-one and in-person, with written informed consent obtained prior to participation. Two research staff and a researcher with lived experience conducted the interviews. To ensure appropriateness in working with marginalized groups, all interviewers were trained in anti-oppressive practices and, whenever possible, participants were paired with an interviewer who shared some aspect of their identity (e.g., Indigeneity). If a participant experienced distress during the interview, a list of community resources was used to refer them to counselling or other supports. Data collection was also overseen by the community-based co-lead of this study, who has experience in trauma-informed practices and was available to support participants and staff as needed. We audio-recorded and transcribed the interviews.

Initially, five academic and community-based research team members participated in collaborative analysis, beginning with data familiarization and discussion of initial notes, and leading to creation of a coding framework through a hybrid inductive/deductive approach.

Thus, some categories were established in advance based on the literature review and logic model, while others were identified through the data familiarization. The coding framework contained nine large domains or topic summaries, most of which contained sub-categories. Two academic researchers trained in qualitative methods tested the framework by each independently coding two transcripts, then one (AS) used it to complete systematic, line-by-line coding of the remaining data. Transcripts were coded using NVivo software (QSR International Pty Ltd., 2018).

Next, the team selected the social context of the encampments as a topic for further in-depth analysis, with a specific focus on mutual support among the residents, as presented in this article. To explore this topic, the lead author (LB) used reflexive thematic analysis to assess manifest and latent content, and identify patterns of shared meaning across the dataset (i.e., themes) (Braun & Clarke, 2006, 2013; Braun & Clarke, 2014, 2019a, 2020). While the focus of this analysis was the broad domain of encampment living and interactions, especially the relationships among encampment residents, all topic summaries were reviewed to identify other material relevant to understanding the encampments' social context. In addition, audio recordings were carefully reviewed to improve interpretation, as the transcripts were often challenging to understand due to interruptions and background noise in the outdoor settings. This practice also helped because participants frequently used slang, non-verbal, or contextually-specific communication. The coded data were reviewed through regular team discussions, and themes were generated and continually refined. We used the concept of information power to determine that we had adequate sample data for this analysis – based on our specific aim, strong dialogue quality, and application of theory (Braun & Clarke, 2019b; Malterud, Siersma, & Guassora, 2016).

To improve quality and rigour of the study, we adopted various techniques within data collection and analysis to facilitate "trustworthiness" of our findings (Guba, 1981). These techniques included: strategies to enhance honesty (building rapport, iterative questioning); enabling triangulation via multiple methods with different informants and data collection sites; collecting rich details about context (setting, participants) and using thick description (reporting relevant background information and lengthier quotes) to facilitate readers' ability to judge meaningfulness for themselves; examining our social positions and assumptions to acknowledge how our beliefs may influence interpretation; documenting and reporting challenges and decisions; and checking our interpretation with community stakeholders (Guba, 1981; Noble & Smith, 2015; Shenton, 2004). We obtained approval from the Unity Health Toronto and University of Ottawa Research Ethics Boards.

4. Results

We conducted 127 quantitative surveys and 23 qualitative interviews with encampment residents between March and June 2021. Mean length of the recordings was 47.5 minutes (ranging from 11 minutes to 1 hour and 26 minutes). Table 1 shows the key demographic characteristics of the interview participants. Participants commonly identified with multiple marginalized groups, including women or gender-diverse, 2SLGBTQ+, racialized (especially Indigenous or Black), and disabled. Most were receiving government disability or social assistance payments, though many also had other sources of income (e.g., street-based activities, such as panhandling), and 52% had lost a source of income since the pandemic started. We interviewed residents who stayed at each of the six encampments visited, though many participants also reported staying at other encampments. Further, 35% of participants were former encampment residents (i.e., they had moved into shelter or housing at the time of their interview). Length of time in the encampments also varied significantly, from weeks to over a year. Many residents described having unmet healthcare needs related to their physical health, mental health, and substance use.

Table 1. Participant demographic characteristics

Characteristic	**Survey responses among those interviewed**
Age	mean = 39 (range = 21 – 64)
Gender*	48% men 43% women 9% trans/non-binary/gender non-conforming 4% preferred not to answer

Sexual orientation*	57% heterosexual 35% lesbian/gay/bisexual+ 4% preferred not to answer
Race*	57% White 35% Indigenous 17% Black 17% other racialized identities
Education	4% none 35% had not completed high school 22% completed high school or GED 13% had some college/university 22% completed college/university 4% preferred not to answer
Income during pandemic*	35% Ontario Disability Support Program (ODSP)** 30% Ontario Works (OW) or social assistance** 9% Any COVID relief benefit, like CERB** 9% family or friends 17% panhandling 17% selling drugs 9% selling handmade goods, crafts, or personal items 4% bottle collection and return 4% sex work 17% other

*Response categories were not mutually exclusive so totals may exceed 100%.
**ODSP refers to disability payments and OW refers to income assistance payments, which are provided monthly by the provincial government. CERB is the Canadian Emergency Response Benefit, which was a $2000 monthly payment provided to Canadians who had stopped working due to the COVID-19 pandemic.

The most prominent influence of the encampments' social context was the mutual support amongst residents. While experiences in the encampments did vary, a substantial majority of participants described engaging in some form of mutual support, with many describing multiple forms. Only a few expressed lacking support from other residents, while a few others did not speak in depth about the topic. Moreover, a majority of participants discussed these supportive experiences in a highly positive manner.

The following themes were identified through our analysis: 1) Encampment residents worked together to manage daily survival needs; 2) Mutual support among residents helped to address many health and safety risks related to homelessness; and 3) The strong sense of community arising from mutual support helped residents meet their health and social needs.

4.1 Encampment residents worked together to manage daily survival needs

Encampment residents described spending a lot of time each day taking care of their basic needs, such as finding food, washrooms and showers, and (for some) drugs, as well as maintaining their makeshift shelter spaces. Residents often worked together to accomplish these daily tasks, providing immense practical support to one another. Many described how they cooperated with other encampment residents to manage their day-to-day survival needs. For example, one participant described how this mutuality played out on a typical day:

> *"You get up, you go bug everybody. Wake everybody up. (laugh) Then we all have a game plan...what are we gonna do today, what do we have to accomplish for the day. … Yeah, so we all kind of come up with a game plan, like, who's going to do what, and who's going to get what for the day. … We all come together basically, and say 'Blah, blah, blah, okay now go.' (laugh) And that's what it's been like. … Yeah, we all know what everybody needs and get it done and that's that. And we all go out for the day, hustle, come back and put it all in a pot, and pool it all together. … It's like a little village, you know? We all take care of each other." (Participant 14)*

Mutual support commonly included the sharing of resources, including donated items, such as food and drinks, tents and sleeping bags, harm reduction or other supplies. Residents also helped each other with maintenance tasks around the encampment, such as securing tents or fixing bicycles. This included responding to weather-related concerns to avoid overheating and dehydration in summer or frostbite and hypothermia in winter. Some residents also helped others by providing information on where to access services or by directing the flow of donations and outreach services to residents who needed them.

> *"And one of the homed residents in particular would come every single day, and I would give him money and a list, and he would go and get me the stuff I needed, at any of the places, for us. And, you know, like all of our overflow went to the other people in the*

> *park. And everyone in the park looked out for each other. You know he would get stuff you already had some, and someone else in the park wouldn't have, so you know, it would go to them. And you know, like any time – 'cause we were the first people there, at the encampment, like, if meal programs or something came in, we would let them know where the other tents were and the other people were. So it was like a really huge community and there was like a lot of love. So I was not expecting that, at all. … I honestly didn't think I could survive it. I thought it would be just me in a tent, and I mean, I didn't have a tent when I started." (Participant 23)*

Almost all participants emphasized that a key benefit of encampment living was being able to watch each other's personal possessions whenever someone had to leave the encampment for errands or any reason.

> *"...sometimes you're not friends with everybody, you just stick to your own group. And I guess it's mostly based on people that you can trust too, like. So the six people that I was with, I would trust them with anything, like I'd just leave my stuff there and I'd go do whatever I need to do. Sometimes we'd organize it like, okay, well I got to leave by this time and do this, so someone has to be at the camp at all times to watch it." (Participant 15)*

Residents often helped to meet each other's needs through dividing tasks and activities according to different people's skills. For instance, some took on a role of "security". This division of labour was dynamic, as people moved in and out of the encampments or residents were displaced due to evictions.

> *"But another guy came to replace him…he turned out to be like a really fabulous cook. And, he moved out of this one situation, but still had access to some stuff. So we ate, like, he brought a lot of food. And he had an income as well. So he did all the cooking. The other guy with the [injury], he would like, do the dishes, and then like, I would do the garbage... And then, you know, me and him would clean up stuff. … We each did what we were able to do." (Participant 23)*

While an encampment leader was identified by some residents, others said that everyone was involved in consensus decision-making and in enforcing rules (e.g., no violence).

Still, many residents highlighted how the encampment social environment worked better than other settings because everyone contributed.

> *"You're not by yourself in the encampment. In the shelter, on the street, you by yourself. But in the encampment everyone has to look out for each other to make sure you're good. Right, that's how you keep a nice home. Everyone plays a part." (Participant 7)*

However, a few residents preferred to fend for themselves in the encampment. Some also described mostly supporting others, rather than receiving much help themselves. Sometimes this was based on who had the resources or existing outdoor survival skills: *"I had lots of stuff, because basically, I was providing clothing for the homeless people, and food. Any homeless was welcome at my place." (Participant 13)*

Those encampment residents who spent a lot of time assisting others expressed pride in helping to create a supportive environment:

"So it built more of a camaraderie, for people had a sense of wanting to be or people to be with. … But it was a place where you could get to know one another and feel safe. ... But, everybody had a sense of being, and ah, that they needed that. And like, I was the one who was giving it, or providing that, and ah, it made me feel important too I guess." (Participant 16)

4.2 Mutual support among residents helped to address many health and safety risks related to homelessness

Residents described facing many health and safety risks due to their homelessness, yet the support received from other encampment residents helped to reduce these risks. As people who use drugs face considerable risk of overdose, heightened since the pandemic (Gomes et al., 2021), this was a critical concern for residents. Many strongly emphasized how they felt safer in an encampment compared with alternative shelter settings, including with respect to both using drugs themselves and other residents using drugs. Many had friends who fatally overdosed after entering the shelter system, and they compared the mutually supportive overdose response efforts in encampments to the inadequate responses in shelters which typically lacked peer-to-peer support.

> *"There's no one to check on you, that's why lots of my friends died in the [shelter] hotel program. Because they're using, like, fentanyl needles and no one is checking on them. Right, so they just sit there depressed in their room and then die. … Yeah, like in the encampments, your friends, like people who will come and say, 'Hey, I'm going to go use, can you come check on me in a bit?' and you go check on them in a bit, right? Because you can." (Participant 6)*

Some residents also expressed how people in encampments respected each other's space so that COVID-19 was less of a concern, and one noted how they worked together to control transmission: "*We're pretty diligent on watching people. You know, see if they're showing any signs of – ... We look out, see if there's any signs of symptoms anywhere." (Participant 8)*

Residents also protected one another from violence, as many described coming to someone's aid to prevent or respond to threatening events. While residents made it clear that violence was a common risk of homelessness, some highlighted the benefit of having "safety in numbers" in encampments. Sexual violence was a particularly significant risk for women experiencing homelessness, and some men described protecting women in the encampments. While some women mentioned receiving assistance from men, they also described working with other women to fend off harassment and violence, and a few noted that they could defend themselves.

> *"Yeah, he watches over me. Like, this one time this guy threatened to rape me. And [friend's name] was the only one, 'cause I guess he was on Dundas, and I was closer to [location] at the time, and he heard me yelling at this dude from Dundas and he came over to check it out. And that's how me and him became friends, because he punched this guy out and got him to go away." (Participant 6)*

Many residents also described facing stigmatization and discrimination from the public due to their visible homelessness. However, some indicated that the support and solidarity they had with other encampment residents worked as a buffer against these negative social experiences.

> *“I really don't give a shit about any of these people who look at us and say, you know what, they want to judge us for living in a camp. Because at the end of the day, they're just one paycheck away from being in the same position. So if they cannot look at us and take an example of the way we strive out here? … Everyone had to, like, keep together and make sure we look out for each other’s stuff, while someone's sleeping and someone's staying up to listen out, like, you know? They're not there. They have their security, we have our community.” (Participant 7)*

Conflicts sometimes occurred amongst encampment residents themselves. Yet some participants noted that these types of conflicts were considered normal or expected because people understood that tensions were high due to the stresses of homelessness.

> *“...it's respect, right? Like, if you don't stop somebody that treats you like that, then it gives everybody else the idea that they can too. … Same with others. So that definitely is what would cause an altercation around here. ... That's one issue right there, I have on the street, we're more likely to get into an altercation. Because the stress of being on the street is so high… And people, a lot of the people, it's like they don't care about their life. Because you see this is your, the rest of your life. So obviously, your care goes lower...” (Participant 19)*

To deal with this issue, residents described their efforts to maintain a peaceful environment in the encampments. Residents employed various strategies to manage conflicts, including discussion or mediation, switching encampment locations or avoiding people until they calmed down, and physical confrontation. For instance, one woman resident described how she intervened when the men fought at her encampment:

> *“And I did a lot of mediating. Cause I got along with everybody in the park. …but a lot of people didn't like each other. So, I was always mediating and having to like, pretend that I was angry to get people to stop fighting. (laugh) … So there's always guys wanting to beat up other guys, so I was always being the one where I'd be like 'Hey - ' You know, using my mom voice, or, or like I said, pretending that I was angry, or disappointed in them, and yelling so that they would stop.” (Participant 23)*

4.3 The strong sense of community arising from mutual support helped residents meet their health and social needs

Residents described providing and receiving extensive social or emotional support within the encampment environment, leading to a deep sense of community among the people living there. Many had pre-existing relationships or developed new relationships with other residents, which provided ongoing social support. Many emphasized finding a positive “community” or “family” among people who they respected and could trust, which was sometimes a sub-group within the encampment. Some participants also noted that they found a sense of community at one encampment but not at another.

> *“Man, more family than my family has showed me, to be honest with you. ... I love this because this is a nice little community. It's not like people think, ‘Oh drugs here and this and that’. No, it’s love here and look out for the brother here. ‘Hey, did you eat?’ Here’s some food. Hey, I got some – I got a shoe that's not fitting, here you go.’” (Participant 7)*

Some participants even described how their relationships with people in the encampments led them to return to visit after they had moved on to other shelter or housing. When one participant who had moved into a shelter hotel was asked if he felt a sense of belonging amongst people in the encampment, he replied: *“Yeah, of course. Of course. That's why I still come back, still come back and visit.” (Participant 7)*

Some residents described how this community connectedness and solidarity was a natural consequence of their exclusion from larger society. They said it helped to find others experiencing similar struggles, including shared material deprivation, isolation, and oppression. A few residents noted feeling more accepted in the encampments for their 2SLGBTQ+ or racial identities.

> *“…there is something to be said for forming a community out of people who don't fit anywhere else in community. And there is something very special about the type of support that it gives to be doing that. And I think that's why it's so commonly done in the way that this is now...” (Participant 12)*

Several residents described that their need for social connection and friendship were a factor in their decision to move to or remain in the encampment.

> *"Because there was people out here I could relate to. … I need people who are like-minded...I need friends who want to hang out with me for just me, and not anything else, right? … And I didn't realize there's a, one lady over there…that like we go out, like, we met each other here. … But her circumstance wasn't about drugs. But she still ended up here. And you know, we still connected. And I don't have to have drugs or I don't have to have money or anything for her to like me. She just likes me for me, you know? … 'Cause I never had that. I always had, like, you know, I've had friends, but it's always been for because I, you know, sell drugs or, you know, I've always been an addict, so I've always had drugs, so." (Participant 22)*

Participants also reported having unmet health or social needs prior to living in the encampments, and that their experience of feeling like they belonged in the encampments helped them to meet these needs.

> *"Some people, they have the mental issue, mental health. Some people have addictions. Some people have anger issues. Some people have different abandonment issues. But everyone has – you just have to have one common ground, alright? What do we all miss? We're missing people who were there for us, right? How can we be there for each other? And even people who don't even understand that, I talked some people down myself too when I showed them that 'Hey, I'm here for you no matter what,' you know, and a lot of people open up to do so." (Participant 7)*

Some residents even credited the encampment community as the main contributor to large, positive improvements in their health status. For instance, when asked to describe the most influential aspect of the encampment on her health, one resident emphatically stated "community" and explained:

> *"It was an easier decision because a lot of people don't understand that people would rather be in a park or that they feel safer in a park than they do in a shelter system. Especially, like, I knew that my mental health would never survive a congregate shelter setting, even without my physical stuff. So it just made it much easier for me to just be able to say 'This is why. My doctor agrees.' … And living in the park was the first place where my mental health, like, I actually started feeling like me again. And it was like, my*

> *doctor...she said she could hear in my voice that I didn't sound completely traumatized. ... You know, like, in whatever many months. Like, it was such a huge difference to my mental health.” (Participant 23)*

In addition, the mutually supportive community environment in encampments allowed for greater autonomy among residents. These settings gave residents an alternative option where they could make their own decisions, often in collaboration with other residents, which contrasted with shelter settings where they typically had to follow strict rules and experienced challenges building social connections (especially during the pandemic).

> *“No, we had to stay in our rooms [in the shelter], quote unquote. Like, we weren't really allowed to go to other, other people's rooms. But over at the park, we could still hang out, still do our thing, you know? And ah, no one – and I don't know if we had decided to put ourselves in a bubble, but you know, we didn't feel that we had to necessarily, um, you know, live in that bubble. You know what I mean? That we, we, cause a lot of people, when you live in a community like this, you go around and you talk to everyone because we all have a different story. So, I wanted to know what other people's stories were, like 'What happened to you? Why did you get here?'” (Participant 22)*

On the other hand, not all participants reported experiencing mutual support and community, and a few mentioned contrasting perspectives, such as instances of distrust or people hoarding resources for themselves: *“I didn't think that there would be as much stealing and ah, as much like, bad things going on...and people screwing each other over.” (Participant 1)*

Similarly, one participant described not having his mental health and social needs met: *“I think I need mental help. … Lots. I need to talk to someone. I need, somebody, just somebody, being human is a social being, you know? It's just so lonely.” (Participant 2)* This lack of mutual support and community meant sometimes having to face threats alone, such as when this participant experienced violent bullying and no one stepped in to help him: *“Everybody thinking about their own survival, you know what I'm saying? Nobody thinking about you.” (Participant 2)*

5. Discussion

Our study looked at mutual support among people experiencing homelessness within the social context of encampments in Toronto during the COVID-19 pandemic. In line with previous scholarship (Dej, 2020; Guirguis-Younger et al., 2014), we found encampment residents described many negative social experiences related to their homelessness, including violence and stigmatization. However, as limited previous research has described (Junejo et al., 2016; Young et al., 2017), we also found that encampments provided residents with a greater sense of community, autonomy, safety and security than other shelter options. This study attended to the knowledge gap on this topic by providing a glimpse into the organic functioning of mutual support systems among people experiencing homelessness in encampments.

It should also be acknowledged that some community groups that formed or existed to support encampment residents operated from a mutual aid model, intending to help disadvantaged community members while emphasising a solidarity rather than a charity approach (Spade, 2020). Such mutual aid groups are known to increase during times of crisis, and COVID-19 was no exception (Mao, Fernandes-Jesus, Ntontis, & Drury, 2021; Spade, 2020; Travlou, 2020). Yet in contrast to these mutual aid groups which included members of the broader community, our findings document the immense importance of the mutual support that occurred directly among encampment residents themselves.

We highlighted three main findings. First, we found that people experiencing homelessness in the Toronto encampments during COVID-19 helped each other in a myriad of ways to meet their daily survival needs. Encampment residents were creative in finding and sharing resources to meet both their own basic needs and those of others, often highlighting the value of reciprocity. Some residents had unique or advanced survival skills which they took pride in using to support others.

Second, encampment residents expressed how mutual support helped them navigate many risks they faced within the context of homelessness, including overdose, COVID-19, physical or sexual violence, stigmatization and discrimination, and conflict with other people experiencing homelessness. For instance, mutual support in encampments acted as a protective factor against overdose risk. By contrast, overdose risk has worsened in shelters since the pandemic, as 2020 saw 46 opioid-related overdose deaths in the Toronto shelter system compared to only 10 in 2019 (City of Toronto, 2021), which may be mainly due to experiencing increased isolation within the new shelter hotel settings that were opened in response to COVID-19 (Gomes et al., 2021). One expected mechanism for the risk reduction and sense of safety and security among residents in the encampments is the trust they had established amongst their "little community".

Third, many participants emphasized that not only did they build their own communities in the encampments, but these communities provided greatly positive social experiences, which is not always the case (Villalonga-Olives & Kawachi, 2017). They expressed the ease with which they developed solidarity with other encampment residents, often due to their shared struggles of homelessness and other forms of marginalization. Feeling like part of a community typically involves the four elements of membership, influence, need fulfillment, and emotional connection (McMillan & Chavis, 1986), resulting in reciprocal social relationships and improved well-being (Bulmer, 2015). Accordingly, many participants ardently conveyed how belonging to an encampment community had improved their lives. This sense of community was also found to be the most prominent theme in the British Columbia encampment study conducted prior to COVID-19 (Young et al., 2017), suggesting that this phenomenon is not exclusive to the particular conditions of this pandemic.

Overall, extensive emotional and instrumental support was demonstrated among encampment residents, while informational support was the least presented. This is in contrast to mutual support groups common in the mental health field, which tend to provide mostly informational and emotional support but minimal instrumental support (Loat, 2011). The emphasis on instrumental support is likely a product of both the socioeconomic deprivation residents faced (making their need for material goods substantial) and the physical circumstances of encampments (providing the space to support each other on a daily basis). In addition, people experiencing homelessness typically face challenges maintaining social connections related to mobility and lack of access to technology to facilitate communication. It is thus not surprising that the close proximity of others in the encampments improved their capacity for community-building.

In addition, the themes demonstrate the importance of self-determination among people experiencing homelessness. Self-determination theory denotes that humans have three innate psychological needs – namely, autonomy, relatedness, and competence – which must be met to achieve personal growth and well-being (Deci & Ryan, 2000). In accordance with this theory, participants demonstrated desires for and benefits from feeling relatedness to others in the encampments, as well as finding competence with respect to meeting each other's needs and improved autonomy in comparison to their experiences in shelter settings. As these core psychological needs are challenging to meet while experiencing homelessness, governmental policies and health or social services should recognize that encampments are people's homes and ensure not to disrupt these communities, consistent with a human rights approach (Farha & Schwan, 2020). Further, our findings highlight the importance of taking a relational view of autonomy that considers social embeddedness and the way oppressive social contexts interfere with people's autonomy. Most participants in this study highlighted negative experiences with respect to the rigid rules and power structures imposed on them in shelters, yet they thrived in encampment spaces where they felt greater freedom and (collective) control over their decisions. As such, our findings challenge paternalistic notions that people experiencing homelessness are not able to make their own best decisions or take care of themselves.

Several studies have also suggested that encampments may be considered a form of protest or resistance, for instance through their focus on community and mutual care as a contrast to the traditional practices of family or institutional care (Speer, 2017; Young et al., 2017). It was clear from our participants' accounts that they felt they could better care for themselves and each other in the encampments versus within any available shelter options. This connects their actions to the mutual aid principle of drawing attention to the inadequacies of existing systems (Spade, 2020). Yet, as with other mutual aid efforts that highlight unjust systems or government inadequacy by demonstrating alternative solutions, encampment residents in our study were often targeted and criminalized. For instance, residents were subjected to displacement from their communities, including by force in the mass encampment evictions of spring and summer 2021 (Wilson, 2021). These evictions jeopardized residents' health and well-being, including by hampering their strong community bonds.

Our findings also highlight that while people in encampments feel ostracized from society, their ability to develop encampment communities demonstrates their resilience, especially in the face of being abandoned by the state during the COVID-19 pandemic. In addition, our findings show that mainstream society did not have a monopoly on whether residents felt a sense of belonging (Dej, 2020), as they intentionally created their own encampment communities which enhanced their social solidarity (Mishra & Rath, 2020). Further, research on homelessness tends to focus on risks, thus neglecting to highlight people's resourcefulness, community connectedness, and achievements (Dej, 2020; Guirguis-Younger et al., 2014). In contrast, our analysis portrayed the highly positive effects of mutual support among our study sample, serving as an example of the ways people experiencing homelessness can take action to care for each other. Although encampments are not a long-term solution to the housing crisis, our findings suggest that as permanent, affordable housing is not immediately available, it is important to respect residents' self-determination and endeavour to 'meet them where they're at'. For instance, encampment residents should not be coerced into indoor shelter settings that do not meet their needs and even pose substantial risks such as fatal overdose (Gomes et al., 2021). Further, our findings corroborate the assertion that social services (including housing models) should honour and reinforce people's existing support networks *within* the homeless community (or other marginalized communities), rather than only focusing on connecting them to social supports *outside* that community (Dej, 2020).

While we found that not all encampment residents experienced the same sense of community and mutual support as others, this often related to how socially integrated their lives had become with those of other residents. Beyond individual preference, some structural factors may have prevented full social integration. First, there were differences in encampment location and living experiences, outreach and nearby services provided, and individual or group characteristics across different encampments. Second, residents were located at encampments of different sizes, for different lengths of time, and at different points in time across the span of the COVID-19 pandemic. All these features may have affected the social context and opportunities for mutual support. Though we did not have adequate data to make comparisons across these many features of the encampments, we suggest they be considered as topics for further study.

While our study had many strengths, such as community co-leadership and centering the often-neglected voices of highly marginalized people, there are some areas where we want to caution interpretation or highlight considerations for future research. First, many community and governmental services or policies were adjusted in response to the COVID-19 pandemic, which greatly affected the lives of people experiencing homelessness (often detrimentally). As such, our findings may be more or less applicable in different crises or in non-crisis times. For instance, encampment evictions occurred more regularly in Toronto before the pandemic, which may have previously disrupted the potential to form communities with quite as extensive mutual support systems. Thus, the potential to improve opportunities for community-building in regular times if such evictions are halted may be even greater. Second, residents of the encampments we visited were frequently in receipt of an outpouring of community support, including from outreach workers and volunteers, with many donations of food, tents, harm reduction and other supplies. Thus, our results beg the question of how much these community supports provided a unique opportunity to improve the social environment of encampments, perhaps creating less scarcity and more stability, which may have facilitated residents' ability to provide mutual support. Future research could directly investigate this question.

6. Conclusions

Encampments promoted opportunities for mutual support and a sense of community among residents, which was highly meaningful and beneficial for people's well-being. Mutual support helped encampment residents meet their basic survival needs, as well as many health and social needs, and reduce many risks. Governments and health and social services should recognize the value of informal support networks among people experiencing homelessness and ensure not to disrupt them, for instance by avoiding practices that displace or isolate people from their communities (e.g., encampment evictions, moving people to shelters located far from their usual supports). Policies and programs to support encampments, shelter settings, and other community services for people experiencing homelessness, may be structured to enhance community-building or reduce barriers such as top-down managerial approaches that amplify power differentials. Finally, co-operative housing models may be most appropriate (Sørvoll & Bengtsson, 2020), providing space for natural communities to develop as well as honouring people’s existing relationships and relational autonomy, thus fostering their capacity for mutual support.

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Chapter 5: Discussion

5.1 Summary of findings

In my **first study**, I examined experiences of self-care among a socioeconomically marginalized population of PWUD. Chapter 2 focused on which self-care strategies PWUD used to manage both their chronic conditions and drug use. Taking a non-disease-specific approach, participants demonstrated a broad view of self-care that included how the strategies they employed also addressed their acute issues as well as serving preventative purposes. This study included participants with extensive multimorbidity and identified a complex interplay between managing drug use and other health issues. While PWUD used many practices common among people with other chronic conditions, such as a range of cognitive and behavioural strategies or seeking out healthcare resources, this research highlighted the need for self-management initiatives among this population to attend further to strategies specific to drug use. Most prominent was the use of non-prescribed drugs for self-medicating other health issues, though managing withdrawal was also critical. Strategies more typically considered harm reduction practices were prominent as well, with the overdose crisis looming large over self-care among PWUD, making practices such as using supervised consumption sites and keeping naloxone nearby commonplace and essential. Yet even among the more generic self-care strategies, some unique types stood out as most important, such as the pursuit of creative activities. Overall, this research highlights the pertinence of taking a holistic approach to self-care that centres the needs, perspectives, and agency of PWUD.

Chapter 3 examined the data from the first study through a relational autonomy lens, investigating the barriers and facilitators to self-care that marginalized PWUD experience. While participants identified some facilitators, such as close relationships, community connections, and helping their peers, they mainly emphasized the many social and economic barriers that substantially hindered their attempts to self-manage health issues and drug use. Most prominently, participants' basic needs were often not met due to unstable housing and inadequate income, which interfered with prioritizing their long-term health issues. PWUD especially considered stable housing as foundational to self-care. Further, participants faced challenges with their social networks and accessing healthcare, including due to stigmatizing interactions with providers. As a whole, this work attends to gaps in the self-management literature around navigating negative social interactions, economic circumstances, and power dynamics, highlighting the need for structural interventions to improve self-care among PWUD.

In my **second study**, presented in Chapter 4, I explored experiences of mutual care among another socioeconomically marginalized population, namely people experiencing homelessness. This study occurred in response to the COVID-19 pandemic and the increase in groups of people living in encampments in parks or other public or private spaces. Unhoused people worked together to establish these encampment communities, which had multiple positive effects on their well-being. In this study, we found that encampment residents provided extensive mutual support to each other, including to help meet their basic survival needs, as well as many health and social needs. Further, they faced many health and safety risks related to homelessness, such as violence and stigmatization, yet the mutually supportive encampment environments helped them mitigate these risks. Like in the first study, the overdose crisis also had a critical impact on participants' experiences, and they felt safer from this risk due to the greater mutual support in encampments compared to shelter settings. Similarly, the encampment environments highlighted the importance of relational autonomy, because participants felt they could take better care of themselves and each other in comparison to shelter settings where they experienced rigid rules and power differentials that interfered with their decision-making and community connectedness.

5.2 Process reflections, strengths and limitations

5.2.1 Engaging with participants and researchers with lived experience

Positionality and reflexivity are critical to ensure that qualitative research is rigorous – that is, considering one's own social position and beliefs and acknowledging how the researcher is central to constructing knowledge through the research process (Finlay, 1998). As with any researcher, academic or professional, I held a certain degree of power over the participant groups in my research. This is exacerbated because the communities studied in this dissertation are socioeconomically marginalized PWUD or people experiencing homelessness. In addition, they are often marginalized in other respects, thus they tend to hold some of the lowest-power social statuses in society. As someone who does not identify with these specific groups, I benefit from the power differential in that respect. However, I am not a service provider or a policymaker, so I do not hold power in that sense (e.g., over people's access to care or other supports). Further, I am a person living with complex, chronic health issues myself. I believe my extensive experiences as a patient enabled me to connect with the participants and community researchers more deeply and to elicit their perspectives with more ease, not only through enhancing my empathy but also through recognizing which questions to ask and how to ask them. Similarly, I purposely engaged with material in the literature that took a critical lens to the dominant discourses within this topic of study (Johnson & Duberley, 2003). I considered both dominant and alternative understandings to inform development of my included research studies and to situate the findings, maintaining an open-minded approach to best reflect and amplify participants' own perspectives.

While my previous education and training background focused more on quantitative methods (including experimental methods such as randomized controlled trials and observational methods such as surveys and administrative database research), I had some prior qualitative experience (Boucher et al., 2017) and further immersed myself in qualitative methods throughout my doctoral studies, which has greatly expanded my overall understanding of the social scientific research process and improved my analytic and interpretive capacity. Given the lack of research on my chosen topic among my population of interest, qualitative inquiry was decidedly appropriate to begin exploring the relevant phenomena. I was able to draw on extensive workplace experience conducting community-based participatory research, including to build on existing connections with members of the relevant communities. Qualitative research methods are highly compatible with community-based research methods, as they both attend to the complexity and nuances of individuals’ experiences, which is supportive for the meaningful, equitable and ethical engagement of people with lived experience (Rolfe, Ramsden, Banner, & Graham, 2018). In addition, the flexibility built into many qualitative research methods, which are more creative than formulaic, provides a basis for cultivating genuine partnerships and soliciting honest input, allowing novel insights to alter both the research process and the individuals conducting it.

As described to some extent within the study articles, it was imperative for me to develop trusting relationships with people with lived and living experience who could act as “gatekeepers” into the marginalized communities of interest in these studies. In Study 1, I drew upon well-known and respected members of the community to introduce me to potential participants and to vouch for me as a trustworthy researcher. In Study 2, I co-led the team in partnership with a well-connected community researcher who provided us with access to a larger group of community representatives who directly supported and had the trust of the community participants. The process of establishing trust with a community ‘liaison’ or ‘influencer’ can be time-consuming but is an essential part of community-based participatory research. This has long been typical within ethnographic research, especially with marginalized and stigmatized groups, but the practice has spread to other community-based approaches.

In addition, having either a Community Advisory Committee or a community co-leader and multiple community representatives to co-design and provide guidance throughout all steps of the studies was crucial to the smooth operation of each study and to ensuring the trustworthiness of the data. For instance, with respect to data collection, these individuals advised on many aspects of the process, including which questions to ask and how to phrase them, the best times of the month or day for recruitment, when other events were occurring in the community that might be disruptive to our process (or which we did not want to disrupt), and which ethical issues were of most concern to the community and how best to approach such topics (e.g., explaining the limits of confidentiality with respect to illegal activities). These types of strategies ensured that the studies were conducted appropriately within their respective communities, and that the information collected was responsive to community needs.

5.2.2 Conducting research in times of overlapping crises

My research studies were situated within multiple, intersecting crises, including the opioid overdose crisis, the housing crisis, and the COVID-19 pandemic. In addition, these crises were layered on a variety of imminent and long-lasting personal crises and challenges that participants (and sometimes community researchers) faced in their day-to-day lives, which included their many acute and chronic health issues and sociostructural barriers, such as stigmatization and discrimination based on identity factors like class, race, gender, sexual orientation, and disability. These factors were sometimes disruptive to the conduct of the studies, especially at the time of recruitment and data collection.

In particular, the overdose crisis presented a substantial methodological challenge in conducting both studies due to the constant death, grief and trauma that occurred in the lives of participants. This not only complicated data collection among participants, sometimes making it hard to discuss certain emotionally charged topics or to divert conversations away from these crises, it also negatively affected the involvement of researchers with lived experience. For instance, research activities often had to be postponed or adjusted because of the announcement of new deaths among friends and acquaintances of the community researchers, including two deaths among our own community researchers. These losses were felt deeply by our research team. In addition, due to the increasingly unpredictable and potent illicit street drug supply, there was a great fear of overdose among the community. The lack of access to a stable, safer supply of drugs was not only a finding of the research, it also sometimes directly affected the conduct of the research. For example, participants had difficulty obtaining the desired dose to meet their drug use and self-medication needs, resulting in them feeling either too high or too low, which they said interfered with their ability to engage in the interview to the full extent they desired. As such, the experiences of PWUD must be contextualized within this ongoing public health crisis.

In Study 1, the impact of the overdose crisis in our setting was anticipated by our community team members. Our study planning occurred in 2019 – several years after British Columbia declared the overdose crisis to be a Public Health Emergency in 2016 – and our community team members who live and work on the frontline of this crisis were witnessing and experiencing the ways that overdoses were increasingly harming Ottawa residents as well. In contrast, the intense influence of the housing crisis on participants' self-care capacity was relatively less expected in advance of data collection, though we did purposefully attend to the social determinants of health in general. Not only did our analysis identify unstable housing as the most fundamental barrier to self-care, but it was also clear that the housing crisis intersected with the overdose crisis in participants' lives. Of relevance, the City of Ottawa became the first in Canada to declare a housing emergency in early 2020 (Osman, 2020) – just prior to the COVID-19 pandemic and during our Study 1 data collection; yet other jurisdictions that have been hit hard by the housing crisis, such as Toronto, have yet to do so (Steer & Bender, 2022).

In Study 2, the research team was explicitly focused on the intersection of the housing crisis and COVID-19, thus the importance of these crises in the findings was not surprising. We were also acutely aware of the long-standing overdose crisis and its overlap with the housing crisis, yet the sheer level of exacerbation of both these crises by the COVID-19 pandemic was staggering (Gomes et al., 2021). Furthermore, COVID-19 resulted in frequent, rapid changes to the services that people experiencing homelessness or PWUD relied on to mitigate risks, many of which resulted in harm (e.g., a reduction in the already insufficient number of shelter spaces and inadequate physical distancing in these spaces). Broad-stroke practice and policy responses to the COVID-19 crisis also affected people experiencing homelessness in unintentional ways (e.g., the closing of businesses that unsheltered people rely on for warmth in the winter). Moreover, the City of Toronto’s response to encampments was directly harmful to people experiencing homelessness and interfered with community efforts to support them. City workers (including outreach workers, parks ambassadors, security, and police) often engaged in surveilling, harassing, and threatening eviction or forcibly evicting encampment residents. This also posed challenges for our data collection with encampment residents, as the threat and act of eviction and enforcement meant that we were unable to recruit people on certain days due to the chaos that ensued from these events. Overall, the need for constant crisis management to address these issues presented many challenges for engaging with both community members and community organizations in Study 2.

5.2.3 General strengths and limitations

In addition to the more specific strengths and limitations outlined within each article, I will further discuss some broader considerations that are pertinent to our methods and findings. First and foremost, the greatest strength of the research studies included in this dissertation is the use of the transformative paradigm to inform our community-based methods in both studies (Mertens, 2007; Mertens & Wilson, 2019). This involved attending to injustice and inequality through recognizing how power and privilege shape the construction of multiple realities, defined by “social, political, cultural, economic, ethnic, racial, gender, age, and disability values” (Mertens, 2007). To do this, I first took extensive time to familiarize myself with the topic and culture of the participant populations. Then, I built trusting relationships with community members with lived experience of socioeconomic marginalization (and other stigmatized identity factors) and engaged them as partners in study decision-making from the very beginning (i.e., to formulate research questions) to the very end (i.e., to translate knowledge to stakeholders). As a team, we considered power issues at every step of the process and were attuned to the cultural complexity of the relevant communities in developing our methodology (Mertens, 2007). For instance, we incorporated specific strategies to cultivate rapport with the expected participant groups, planned how to phrase and rephrase questions in ways that would facilitate understanding amongst diverse individuals, and choose recruitment dates, times, and locations to be the least intrusive to regular community activities and needs. We also refrained from beginning with too-narrow interview questioning to encourage participants to lead the conversations. This was a vital practice to determine which aspects of the topic were most important to them and to avoid the imposition of normative perspectives which may have interfered with obtaining their often-excluded viewpoints. Further, community and academic researchers analysed and interpreted the data together while considering the influence of discrimination and oppression. Overall, through following the transformative approach and meaningfully engaging people with lived experience, we were able to prioritize and amplify the voices of marginalized communities, which enhanced the trustworthiness of our findings and provided a substantial basis for challenging dominant perspectives that did not reflect the needs of these communities, and sometimes actively harmed them.

In addition, for both of these studies, I purposefully employed a qualitative analysis approach (i.e., reflexive thematic analysis) that was accessible for working with marginalized groups and large research teams, including individuals who had wide variation in backgrounds and level of experience with qualitative inquiry (Braun & Clarke, 2014). This approach paired well with community-based participatory research methods because it was highly flexible and did not enforce strict commitment to particular theory or procedure, which allowed us to adapt to the needs of relevant contexts and iteratively adjust our process throughout (Braun & Clarke, 2006; Braun & Clarke, 2014, 2019a). In addition, reflexive thematic analysis was suitable to our mainly inductive, open-ended, and exploratory approach across the articles, aspects of the studies which also helped to ease the involvement of non-academic community researchers in analysis. This qualitative approach further highlights that researcher subjectivity is a resource in qualitative research, with the understanding that knowledge production is about interpretation and meaning-making rather than discovering objective truths (Braun & Clarke, 2019a). The process thus required extensive engagement with the data in deeply thoughtful, reflective, and creative ways, rather than relying on positivist ideals such as reliability or consensus across coders (Braun & Clarke, 2019a). However, to improve interpretive power and permit analytic claims beyond simple description, I incorporated theoretical and conceptual frameworks in all studies (Braun & Clarke, 2006). By following these practices, I was also responding to calls to advance critical qualitative inquiry within health research by prioritizing depth over breath and “moving beyond the reproduction of dominant ways of understanding the world”, a practice which contributes to “raising the level of excellence of the field methodologically and theoretically” (Eakin, 2016).

Accordingly, I also employed the newer concept of “information power” (Malterud, Siersma, & Guassora, 2016) to determine that the study sample sizes were adequate for the analyses across my articles, in contrast to the more common concept of “saturation”. This decision would benefit from a bit more explication. First, saturation was originally intended for use within the grounded theory approach, termed “theoretical saturation” and related to practices of theoretical sampling and constant comparison (Malterud et al., 2016; Saunders et al., 2018). However, it has come to be used across a much wider variety of approaches in what appears to be multiple different (and often unquestioned) ways, with authors typically providing minimal justification for their use (Braun & Clarke, 2019b; Saunders et al., 2018). Further, samples in qualitative studies are often multiples of ten, suggesting that sample size may be more influenced by pre-determined calculations than saturation, which is generally considered antithetical to principles of qualitative research (Saunders et al., 2018). Second, while saturation may have a useful role in some qualitative approaches if employed thoughtfully, it is mostly not a meaningful concept within the context of reflexive thematic analysis (Braun & Clarke, 2019b). This is the case for multiple reasons, including because saturation as “information redundancy” (as it is most commonly defined) relies on assessing code and theme frequency, whereas reflexive thematic analysis involves coding that is constantly evolving throughout analysis and emphasizes theme quality and relevance to the research question (Braun & Clarke, 2019b). Alternatively, having sufficient information power denotes that sample size should be based on where a study lies on the continuums of (at least) five factors – with a narrow study aim, more sample specificity, application of established theory, strong dialogue quality, and a within-case analysis strategy all suggesting that a smaller sample is sufficient (Malterud et al., 2016). In this way, my research studies respond to current tensions within the qualitative paradigm. In general, information power emphasizes that qualitative research should aim for new knowledge rather than a comprehensive understanding of phenomena (which is implied by saturation), with the concept representing one aspect of the internal validity (or “credibility”) necessary to produce new insights (Malterud et al., 2016).

Finally, the studies included in this dissertation should be considered carefully with respect to external validity or generalizability. While qualitative research is typically focused on hypothesis-generating versus hypothesis-testing, this does not imply that no generalizations should be made. Yet, rather than statistical generalizability, the concept of flexible generalizability is applicable. Flexible generalizability involves “sensitivity to context and the flexible nature of language” (Braun & Clarke, 2013), though this is most commonly termed “transferability” in qualitative research. That is, authors are expected to provide enough specific details about settings, participants, and circumstances to allow readers to decide if ‘transfer’ to other contexts is warranted (Braun & Clarke, 2013). Similarly, rather than more nomothetic or horizontal generalizability, vertical or analytic/idiographic generalizability is more applicable in qualitative work, involving in-depth interpretative analysis of the specifics of a study to make context-specific statements, rather than aiming for universal or statistical laws or rules (Braun & Clarke, 2013; Mayring, 2007). Given both of my included studies were exploratory, some caution is warranted in determining how to apply the lessons to other contexts; however, we found several pervasive themes which are anticipated to withstand transfer. For instance, for Study 1, given the breadth of the topic more research is needed on certain aspects, yet the most prominent themes (e.g., managing health issues through self-medication) will likely hold for similar contexts and participants. For Study 2, attention should be given to the nature of the physical and geographical environment, as well as the political and social context of the pandemic. However, these findings also benefit from being part of a mixed methods investigation in which a larger sample was surveyed, and different stakeholders were interviewed, which both corroborate different aspects of the findings (e.g., providing much information on other living settings to compare to people’s experiences in the encampments). While these studies may be considered to have small sample sizes, especially from a positivist lens, this critique is an inadequate basis to judge generalizability if data adequacy is demonstrable based on intrinsic features of studies, such as richness of data and analysis qualities (Vasileiou, Barnett, Thorpe, & Young, 2018). Further, while the ability to make generalizations from a single study is more limited in qualitative research, identifying points of synthesis across multiple studies with different data sources, contexts, and populations provides a form of triangulation (Mayring, 2007). This includes using existing literature and theory to situate these results within the broader context, a key strategy in my dissertation studies which facilitated obtaining a richer understanding of phenomena (Braun & Clarke, 2013; Mayring, 2007).

5.3 Synthesis of contributions

In their entirety, the three articles within this dissertation make several contributions to advancing the scholarship in this field. First, they demonstrate how the socioeconomically marginalized groups of PWUD and people experiencing homelessness actively employ many alternative and holistic practices of care to meet their health and social needs. Second, they highlight the critical limitations that structural and systemic factors impose on the self-care and mutual care efforts of these groups. Third, they emphasize the substantial influence of these groups' social environments in constraining or supporting their health and well-being, highlighting the need to incorporate more relational conceptual models. Overall, these three contributions make progress toward addressing the inequities in self-care support among marginalized groups. I will describe each of these contributions in further detail.

5.3.1 Alternative and holistic practices of care

The first key point of synthesis across all three articles centered around the use of what may be considered "alternative" strategies or practices to care for oneself and one's peers, in comparison to those of more traditional health and social care services. For example, the types of decisions and actions that participants took demonstrate the importance of agency or autonomy in shaping how they managed their health and social needs. In Study 1, PWUD chose self-care strategies that fit best within the challenging circumstances of their lives (e.g., adopting self-medication and harm reduction practices because they did not have access to pain medication or a safer supply of pharmaceutical-grade drugs). Similarly, in Study 2 people took it upon themselves to create their own living environments, often to avoid institutional shelter settings. They shared many inventive survival skills and ultimately developed communities, expressing that they preferred the encampment environment because it allowed them to work together to meet their own needs better than they could in shelters. In both studies, being able to make their own decisions with minimal interference was critical to meeting their needs. However, the practices that participants employed are usually deemed unacceptable to other people in society, and moreover, they are criminalized (e.g., using illicit drugs or camping in parks are both currently against the law). Further, these practices are often not recognized as legitimate self-care or mutual care practices by traditional institutions. Thus, mischaracterizations abound about PWUD and people experiencing homelessness as being either not willing or not able to care for themselves – notions which are not supported by the studies in this dissertation, especially given that the main reasons why their care practices were not sustainable involved structural barriers (e.g., lack of treatment access, police intervention).

Most existing health and social services, along with the criminal justice system, are designed in ways that work to “manage” the individual behaviour of people experiencing marginalization who rely on such services, including people experiencing homelessness and PWUD (Dej, 2020). This means these individuals are typically required to behave in certain ways to be eligible for such services. These populations have a well-documented history of institutionalization, as well as long-time stigmatization and discrimination against their many marginalized identities. Hence, power differentials were strongly emphasized across the studies as an interfering factor, and participants described feeling patronized or judged while interacting with health and social care systems. All these factors are likely culprits contributing to the distrust and avoidance of formal institutions among many individuals. Still, given that both studies identified a preference for alternative practices that were mostly self-directed (though often in collaboration with their own communities), while also highlighting the ways that these practices were impeded by traditional models of care, the value of bottom-up, person-led approaches is evident.

Some might even call these practices “radical” and thus a form of resistance or protest (whether intentional or unintentional) against oppressive or controlling systems of government and institutions. For instance, some PWUD in Study 1 talked about not having the goal of becoming fully abstinent from illicit drugs, which is traditionally at least an eventual goal in most care models. Such resistance to traditional models of care is further shown in the intentional creation of mutual support systems within the encampments in Study 2. At the very least, they demonstrate the resilience of these communities, especially in the face of social exclusion and government neglect or criminalization. Many people asserted that they knew what they needed in terms of supports to address their health and social issues, yet institutional practices of care were either not accessible to them or did not work for them; thus, given their limited options, they were managing as best as they could. This action of rejecting mainstream systems or practices when they are seen as unjust or inadequate is an important expression of autonomy and perhaps one of the few ways that marginalized groups take back some power in their lives.

The self-determination theory further helps draw together several components of the different findings. Participants across the two studies showed intrinsic motivation and took action to meet their three psychological needs – that is, belongingness, autonomy, and competence (Deci & Ryan, 2000). Belongingness and autonomy were demonstrated most prominently, though competence was evident in more subtle ways. For instance, people’s engagement in creative pursuits in Study 1 was connected to their desire to feel a sense of accomplishment, while in Study 2 people highlighted feeling proud of how the encampments that they had helped establish were so beneficial for their own and others’ well-being. Also interesting was how autonomy was connected to the importance of people’s peer and mutual support practices in both studies, which supports the use of relational autonomy (discussed further below).

In addition to engaging in alternative practices to meet their needs, participants across the studies often expressed alternative conceptualizations of the overarching topics. That is, they considered both the concepts of "health" and "care" in more holistic ways (considering the "whole person" and the "body-mind-spirit") as compared to more traditional (biomedical or even biopsychosocial) definitions (Frisch & Rabinowitsch, 2019). This aligns with, and even extends beyond, trends in recent years toward broader conceptualizations of health (Huber, 2011; Jambroes et al., 2016) and care (The Care Collective, 2020). This tendency toward broad conceptualizations of health and care is also demonstrated in the overlap between what people considered to be both self-care and harm reduction practices, which was shown in Chapter 2 and which I also found in a previous study focused on harm reduction (Boucher et al., 2017). Overall, this finding depicts the value of qualitative methods in delineating these complexities and nuances in different understandings of phenomena, which helps continually refine the relevant bodies of literature and ensure they reflect people's lived experiences.

This finding also highlights the utility of research that privileges "first voices" (i.e., people with lived experience) in order to question dominant norms, expectations, and framings, especially among marginalized groups (Dej, 2020). Listening to and centering the perspectives of people with lived experience can reorient and challenge common discourses, including by shedding light on the aspects of experience that impact them the most. Further, the increasing focus on health inequities in public health and healthcare delivery demonstrates the imperative of inclusivity, especially to redress past neglect of certain groups' perspectives. In my dissertation studies, this practice demonstrated the strengths and resourcefulness of people experiencing socioeconomic marginalization, while emphasizing the persistent ways that structural barriers hinder their efforts. Ultimately, the findings in this dissertation suggest that many current services (including homelessness and self-care supports) are unlikely to meet the needs of people experiencing socioeconomic marginalization without adapting to centre the autonomy and expertise of these groups, thus including them in co-design of their own care.

5.3.2 Socioeconomic and other structural barriers

The second key topic that links the findings across the studies, especially evident in Chapters 3 and 4, is the prominence of widespread structural and systemic barriers in constraining these marginalized groups' ability to meet their needs (e.g., inadequate housing or income supports, inaccessible healthcare, stigmatization and discrimination). These groups also face many well-known inequities with respect to the social determinants of health, including adverse early childhood events, food insecurity, housing instability, and social isolation (Public Health Agency of Canada, 2018). These factors have been shown to account for between 30-55% of people's health outcomes, often outpacing the impact of lifestyle or healthcare factors (World Health Organization, 2022). Yet the often-unseen nature of social determinants of health and structural barriers contributes to misperceptions that socioeconomically marginalized groups are not attempting to improve how they manage their health and other needs, rather than how often these attempts prove futile due to such barriers. In fact, the World Health Organization (2022) denotes that on a global scale, there is a clear social gradient indicating that health outcomes are worse at low socioeconomic positions.

The studies within this dissertation deliberately sought to understand the barriers that participants faced while trying to address their health and social issues, answering the call to avoid the common individualization of problems with sociostructural causes and instead reorienting approaches to highlight how to address these root causes (Dej, 2020). Among PWUD or people experiencing homelessness in the included studies, the most critical structural barrier was inadequate housing support. Given the long-time affordable housing crisis in our setting, this was not surprising. Inadequate income support was also a prominent barrier, which is related to housing issues (and to the definition of our study populations of course, as was housing issues in Study 2). Together, these issues stem from policies of the Canadian welfare state which have for decades increasingly embraced neoliberalism and neglected the need to invest in social housing (Dej, 2020). Further, COVID-19 has inequitably exacerbated pre-existing socioeconomic marginalization (Bryant, Aquanno, & Raphael, 2020; Shadmi et al., 2020). Additional systemic barriers identified in the studies were related to policies of criminalization, such as the difficulty PWUD had in attaining a safer supply of pharmaceuticals or even medication for their chronic pain, as well as the challenges that evictions and violence from the state posed to the supportive communities that people had built within the encampments. Encompassing all these issues is the pervasive societal stigmatization and discrimination of both PWUD and people experiencing homelessness, which permeates all the relevant systems and sectors and often propels decision-makers to establish policies and programs that affect these marginalized groups based on public perception (which is also biased by stigma) rather than the best available scientific evidence. Such stigma as well as other policies related to healthcare provision have also resulted in insufficient access to multidisciplinary pain management and mental health or addiction treatments, especially for socioeconomically marginalized groups (though these are wider system gaps, the historical lack of prioritization at least partially stems from the stigmatized status of these conditions). Overall, these barriers were highly detrimental to both self-care and mutual care efforts in the two studies, leading to increased mental distress, worsening of physical conditions, and isolation from social supports.

The findings across these studies are in accordance with Maslow's (1943) classic hierarchy of needs, denoting the need to address basic physiological and safety needs prior to psychological needs such as belongingness or esteem. While there have been updates and critiques of Maslow's hierarchy, the primacy of basic needs and the immense importance of social affiliation have been less debatable aspects (Kenrick, Griskevicius, Neuberg, & Schaller, 2010). Yet all of these lower-level needs may be considered "deficiency" needs, in contrast to higher-level "growth" needs such as cognitive and aesthetic needs (Maslow, 1981). Participants in both studies were often inhibited in achieving progress on their growth needs due to the need to prioritize their deficiency needs, yet this did not mean that they lacked higher-level goals or were not attempting to strive for those goals at all. In fact, some expressed working toward those goals at the same time, but often described the ways that persistent structural barriers interfered. This was especially true in Study 2, where participants more often lacked physiological and safety needs, yet they were actually able to meet their belongingness needs (and to some extent esteem needs) to a greater extent than participants in Study 1. This is an interesting contrast because it denotes that not only can social needs be cultivated in times of acute economic crisis (when meeting basic survival needs are the most urgent challenge), but that meeting social needs in these situations contributes to survival (including to meet both physiological and safety needs).

Part of why these structural factors were so disruptive to self-care and mutual care are because they interfered with people's autonomy to care for themselves and each other in the ways they preferred (as noted above). For example, encampment evictions forced some people to enter shelters despite not wanting to leave their encampment communities. In addition, these structural barriers harmed people's ability to maintain social connectedness. For instance, this is evident from the challenges participants of both studies experienced in trying to remain connected to their social networks and community supports while they lacked stable access to technology. While technological access was an existing issue prior to COVID-19, it has been exacerbated by the pandemic-related changes to supports and to society at large, further enhancing inequities for people experiencing socioeconomic marginalization (Bowman, Seehusen, & Ledford, 2022). This is especially problematic as computer and mobile technology is increasingly used to deliver self-management supports (McCabe, McCann, & Brady, 2017). Similarly, lack of income was related to issues like reduced mobility, which was also cited in both studies as a challenge for maintaining social supports, yet in Study 2 people were able to overcome this through their close proximity within the encampments.

5.3.3 Social environments and support networks

Finally, the studies are well connected through the thematic prominence of social factors affecting socioeconomically marginalized groups, which permeates most fully Chapters 3 and 4. The prominence of socially-relevant themes was evident across both studies, and within these themes the peer and mutual support aspects were especially prominent. While many participants described experiencing negative effects from social isolation, stressful or chaotic social environments, and stigma or discrimination, our studies also demonstrated that on the occasions in which participants were able to find supportive relationships or communities, they experienced highly positive effects and were exceedingly grateful. Compared to those who were not well-integrated socially, people in both studies with better social networks displayed greater health and well-being, and many explicitly attributed their improvement to gaining meaningful social support or community connectedness. Moreover, among most participants in both studies, caring for their peers seemed to have an equally beneficial effect on their health and well-being as did having others care for them. Further, receiving or providing such peer support increased people's motivation to continue improving how they cared for both themselves and others. Both studies also demonstrated that it was easier for people to develop solidarity and build communities with other people with lived experience, due at least in part to their shared struggles.

Still, the social issues that people across these studies experienced were pervasive and it is important to understand how their challenging social environments contextualize the positive findings. PWUD and people experiencing homelessness both discussed being socially excluded from wider society and facing stigma and discrimination from the public. They also described how a lack of emotional supports and some conflicts with their peers was typical, though this was rectified for many participants in Study 2 through the mutually supportive encampment environment, which facilitated trust and communal conflict management. Similarly, while participants described having few instrumental supports in their usual day-to-day lives, the encampment environment was again unique in facilitating opportunities for this type of support (e.g., residents shared food and other supplies). Interestingly, despite participants in Study 2 experiencing more extreme material deprivation, participants in Study 1 noted that their limited material means was more of a barrier to supporting each other. Thus, in Study 1, a prominent suggestion was to increase opportunities for paid peer support positions to facilitate such helping behaviours, likely because this practice would be congruent with the current structure of people's social contexts. Yet, it seems likely that more broadly changing the structure of people's social contexts to typify the community-building elements of the encampment environments would result in better overall outcomes. Further, formalizing peer support poses a risk if not actually peer-led, such as when these initiatives are led by institutions that have previously harmed marginalized groups. Using peers to gain trust may result in further marginalization if the institutions continue to discriminate in other ways.

While formal peer support was also important to the participants, these studies mainly shed light on the under-researched area of informal peer support (which tends to be more reciprocal) among socioeconomically marginalized communities, including among two groups who are highly stigmatized and excluded from broader society. There is a long history within the mutual aid/self-help group tradition of populations who have been excluded or stigmatized by mainstream society (Katz, 1981; Katz & Bender, 1976). This is not surprising as these populations likely have a greater need for such supports because existing institutions (including both formal care services and the traditional family unit) are often unable to meet their needs (Speer, 2017; Young, Abbott, & Goebel, 2017). Overall, it is important to understand and acknowledge the nature and value of such informal supports, recognizing that despite being socially excluded these groups can harness supports within their own communities, and that these practices may be best fostered through structural changes (e.g., particular housing models).

Yet, as the medical self-care field has detached from the historically more natural and informal mutual aid/self-help groups, one possible issue is a resulting (sometimes unconscious or implicit) emphasis on practising self-care by oneself or being solely "responsible" for one's own care. This is a potentially problematic conceptualization that is unlikely to represent people's lived experiences, given the social nature and interdependence of (self-)care activities. Further, given that illness and social disadvantages tend to be highly isolating, and loneliness is a key contributor to negative health outcomes, the individually-oriented focus of such initiatives may contribute to further isolation. Relatedly, the goal of increasing "responsibility" among patients is prevalent across typical self-management initiatives within public health systems (Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011; Kennedy, Rogers, & Crossley, 2007), consistent with neoliberal responsibilization and suggesting a 'co-optation' of self-care from the communities in which it originates, as has been noted with respect to the appropriation of harm reduction within public health initiatives (Smith, 2012). Thus, self-care initiatives built from a more grassroots, mutual aid/self-help group approach may be more appropriate and result in greater and longer-lasting benefits for marginalized populations.

On the whole, our findings concur with and extend critiques of the patient- or person-centered care concept that have identified confusion and advocated for more relationship-centered approaches including “authentic partnerships” (Dupuis et al., 2012; Nolan, Davies, Brown, Keady, & Nolan, 2004). Similarly, approaches such as considering a ‘patient nexus’ support these shifts, which includes attention to social ties as well as social capital (Tausig, 2013). Further, some have even called for a transition from patient-centered to community-centered approaches in medicine, such as honouring the potential of collective action to transform patients’ lives and thus providing referrals to relevant community organizing groups (Morris, 2019), which may be especially helpful for people experiencing some form of marginalization or social exclusion. Similarly, the work in this dissertation demonstrates the value of taking a relational view of autonomy, especially when investigating groups who are embedded within oppressive social contexts. Relational approaches have also been advocated in other areas, including to enhance shared decision-making in clinician-patient relationships (Lewis, 2019) and to build a public health ethics framework to support dealing with issues such as pandemics (Baylis, Kenny, & Sherwin, 2008). Compared to past self-care research, applying a relational lens provided a more nuanced yet trustworthy picture of how socioeconomically marginalized groups care for themselves and each other. Critically, these care efforts cannot be divorced from the social context of these groups, which requires them to expend much effort to cope with obstacles from government, care services, or the public in general, including the widespread stigma and discrimination, criminalization, and displacement from their communities, all of which increase their vulnerability to violence and other harms to safety, health and well-being.

5.4 Implications and future directions for research, practice and policy

Several implications and directions for future research, practice and policy extend from this dissertation. First, among socioeconomically marginalized groups, health promotion efforts that encourage self-care or mutual care must also include a focus on addressing the social determinants of health and structural barriers that contextualize and constrain people's behaviour. This should include recognition that these groups' actions are not simply 'risk factors' (as often depicted in public health) but are adaptive for survival within their challenging contexts, as well as understanding that their basic needs must be prioritized before other actions, thus the best support would be to ensure that adequate economic resources are available for these communities. It is important for future research to incorporate conceptual frameworks that highlight structural components, such as a structural vulnerability framework (Bourgois, Holmes, Sue, & Quesada, 2017), or the social ecological model (Bronfenbrenner, 1977, 1979) which has been updated to suggest a greater focus on policy and environmental change (Golden, Mcleroy, Green, Earp, & Lieberman, 2015). Moreover, it is a government imperative to address the lack of affordable housing given the current scale of this crisis. Similarly, especially given increasingly massive casualties from the overdose crisis, another long-overdue government imperative is to replace the toxic street drug supply with a safer supply of pharmaceutical-grade drugs. In addition to policy changes, these actions will require advocacy for health and social systems-level changes, as well as ongoing implementation research to improve delivery and impact of these initiatives.

Second, based on the findings in this dissertation, I propose shifting focus within several areas of scholarship and practice when working with socioeconomically marginalized groups. First, shifting from patient/person-centered care to either relationship- or community-centered care (which may be relevant in different contexts) would be beneficial to acknowledge the influence of social support networks and social capital among these groups. Second, shifting from an individualistic conception of personal autonomy to a relational conception of autonomy would increase understanding about people's social embeddedness and the importance of collective agency. Lastly, reflecting the two previous proposed shifts, self-care initiatives for socioeconomically marginalized communities may be best re-designed as mutual care initiatives, recognizing the importance of community-centeredness as well as how relational autonomy is essential to understanding self-care (Ould Brahim, 2019). This is especially important to adequately situate people's behaviour within (often oppressive) social contexts and avoid overreliance on individualizing their distress and medicalizing social problems (Dej, 2020). Mutual care initiatives are expected to be of greater value for socially excluded communities, such as PWUD and people experiencing homelessness. Relatedly, public health and healthcare initiatives would be well-served to incorporate holistic and relational understandings of health and care into usual practice, focusing attention on (often-neglected) socially-relevant interventions and outcomes to better represent people's everyday lived realities and enhance overall well-being, especially to support addressing health inequities among socioeconomically marginalized groups. This will involve all stakeholders (researchers, practitioners, policymakers and other decision-makers) recognizing the importance of including meaningful engagement of people with lived experience as well as qualitative inquiry that centres marginalized peoples' voices in designing and evaluating such initiatives.

Finally, we need further research and program evaluation to determine how to best promote (or at least not interfere with) self-care and mutual care among socioeconomically marginalized communities. Health and social services, including housing supports, may need to either develop new supports or adapt current supports in ways that enhance autonomy but also collectivity, explicitly incorporating opportunities in ways that allow mutual support and collaboration to flourish organically. This approach involves recognizing that people with lived experience know their own needs the best and are the experts on their own self-care. As such, they should be given the resources, space, and decision-making capacity to direct service provision, while still being offered guidance on this process as desired. Formal services may also be better structured to support people's self-care and mutual care activities, such as through enhancing outreach and low-barrier drop-in services that 'meet people where they're at'. With respect to developing more affordable housing specifically, this may involve considering alternative housing models which promote both autonomy and community-building, such as some co-operative housing (Sørvoll & Bengtsson, 2020). Further, given large numbers of socioeconomically marginalized Indigenous peoples and the need to respect multiple ‘ways of knowing’, it may also be important to embrace Indigenous concepts such as “non-interference” (Wark, Neckoway, & Brownlee, 2019). Considering how the formalization and medicalization of self-care and mutual care phenomena may hinder some important benefits for marginalized groups, future initiatives should proceed cautiously and conduct research to investigate potential risks such as co-opting the leadership and management of such initiatives from people with lived experience.

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