Assessing consumer perspectives on population need for substance use services

by

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Abstract

Effective substance use services often fail to reach many people experiencing drug or alcohol problems in the community. Recognition of this large treatment gap has stimulated efforts to better align service systems with existing population need. A growing body of research assesses population need by estimating the prevalence of substance use disorders using objective, expert-defined measures. Subjective, consumer-derived need measures have the potential to enhance this work and improve its relevance for service planning, but it is unclear how frequently consumer perspectives are incorporated into the literature on population need for substance use services. Additionally, few studies have assessed consumer perceptions of need amongst socially marginalized, hidden populations, despite their increased likelihood of experiencing substance use disorders and related harm. In light of these knowledge gaps, this dissertation had two broad objectives: (1) systematically describe and map the literature on population need for substance use services; and (2) examine consumer perceptions of service need among a sample of street-involved people who use drugs. Two studies addressed these objectives: a systematic scoping review assessing 1930 articles on population need for substance use services, and a survey of 320 street-involved people who use drugs.

The vast majority of research on population need for substance use services prioritizes objective, expert-determined need estimates, with only a small fraction of studies reporting data on subjective need. Those studies that do assess consumer perspectives have several methodological and measurement weaknesses, including a tendency to estimate need for one type of service only, which limit their utility for system planning. When consumer perceptions are assessed across several service categories, street-involved people who use drugs report high rates of perceived unmet need and self-assessed barriers to services. However, participants' levels of unmet need and barriers vary considerably across services, and socioeconomic marginalization and problem severity increase the likelihood of reporting unmet need for some services, but not others. Taken together these findings imply that different factors both predict and underlie perceived unmet need across various kinds of substance use services, and that a large proportion of extant research may not be capturing this complexity.

There are a number of ways to improve research on consumer perspectives and population need for substance use services. In particular, the concept of subjective, consumer-defined need should be further refined

and standardized instruments capable of assessing consumer perspectives across a variety of substance use service categories should be developed. This work is necessary to enable a more nuanced investigation of factors underlying the substance use disorder treatment gap for both general and hidden populations, and to improve the ability of research in this area to inform substance use service planning. Robust research on consumer perspectives within the literature on population need for services is overdue. An emerging public health approach to substance use provides an opportunity to unify and advance multidisciplinary research on consumer perspectives, and leverage their full potential to reduce the population burden of substance use disorders.

Preface

This statement certifies that all of the work presented henceforth was conceived, undertaken and written by the candidate, Elaine Hyshka. All research involving human participants was approved by the University of Alberta's Health Research Ethics Board, Project Name "Risk Behaviours and Service Needs of Marginalized People Who Use Drugs in Edmonton's Inner City", No. 43407, March 13, 2014. Dissertation collaborators include Dr. T. Cameron Wild (TCW), Dr. Tania Bubela (TB), Dr. Candace Nykiforuk (CN), Ms. Jalene Tayler Anderson (JTA), Ms. Gaju Karekezi (GK), Mr. Benjamin Tan (BT), Ms. Linda Slater (LS) and Mr. Jesse Jahrig (JJ) made contributions only as is commensurate with supervisory committee, or co-investigator duties. Relative contributions of each collaborator are outlined below.

Chapters 1 and 4 are original, unpublished intellectual products of the author. EH searched and synthesized the literature cited, and wrote each chapter with guidance from TCW, as well as supervisory committee members, TB and CN.

Chapter 2 is original research in preparation for submission for peer-reviewed publication under the co-authorship of EH, GK, BT, JJ, LS, and TCW. EH designed and led the systematic scoping review. TCW as the supervisory author provided oversight during development and implementation of the study. LS, EH, JJ, and TCW designed the search strategy and LS implemented it. GK, BT, JJ assisted with the selection of studies for inclusion, and coding of included studies. EH conducted the analysis and prepared the manuscript with significant input from TCW, and additional feedback from TB and CN.

A version of Chapter 3 has been submitted for peer review: Hyshka, E., Anderson, J.T., and T. Cameron Wild. "Perceived unmet need and barriers to care amongst street-involved people who use illicit drugs." EH and TCW designed the study. EH and JTA collected the data. EH took the primary role in analyzing the data and prepared the first draft of the manuscript. TCW provided input on the draft, and JTA, TB, and CN provided additional feedback.

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List of Abbreviations

AOR: Adjusted odds ratio.

DF: Degrees of freedom.

PWID: People who inject drugs.

PWUD: People who use drugs.

PNCQ: Perceived Need for Care Questionnaire.

SE: Standard Error

SM: Substance misuse.

SUD: Substance use disorder**.**

Chapter 1: Introduction

This dissertation contributes to the literature on measuring population need for substance use services, with an emphasis on understanding the potential of a subjective, consumer-defined approach to enhance substance use service system research and planning. It adopts a paper-based format and includes an introduction chapter, two journal articles (Chapters 2 and 3), each reporting the results of original research, and a conclusion chapter. Chapter 2 reports the results of a systematic scoping review of the literature on population need for substance use services (**Study 1**). Chapter 3 reports the results of a survey assessing the mental health and substance use service needs amongst a sample of street-involved people who use drugs (**Study 2**). The concluding chapter synthesizes the main dissertation findings, outlines avenues for further research, and suggests some policy and practice implications.

This Chapter reviews the epidemiology of substance use disorders in Canada and internationally, discusses societal responses to mitigating substance-related harm, outlines a public health approach to substance misuse, and provides an overview of substance use service system research and planning. I conclude by outlining the rationale for both dissertation research studies, and specifying the research questions addressed in each.

Epidemiology of substance use disorders

Substance use patterns vary along a spectrum from beneficial to harmful use - the majority of people using licit and/or illicit psychoactive substances do not experience significant harm or substance use disorders (SUDs) (Caulkins, & Reuter, 1997; Catford, 2001; Kalant, et al., 2015; Government of Canada, 2012). For a minority of users, however, problematic patterns of alcohol and other drug use can result in many adverse consequences, and represent a major public health challenge resulting in significant morbidity, mortality and economic costs. At the individual level, substance misuse (SM) is associated with a range of negative health outcomes, and can result in mild to severe SUDs, acute and

chronic toxicity-related morbidity and mortality, accidental injury, mental health problems, experiences of violence, chronic disease, and self-harm. Alcohol misuse increases the risk of malignant neoplasms, diabetes mellitus, cardiovascular problems, and liver cirrhosis (Rehm, et al., 2009), whereas illicit drug misuse (particularly involving injecting) may increase propensity for Hepatitis C, HIV, sexually transmitted infections, cutaneous and subcutaneous abscesses, endocarditis, and talcosis (Degenhardt, & Hall, 2012).

At the population level, mental and substance use disorders are the leading global cause of nonfatal burden of disease, and in 2010 accounted for 183.9 million disability-adjusted life years (DALYs) or 7.4% of all DALYs worldwide (Whiteford, et al., 2013). SUDs are significant contributors to this global disease burden, representing 10.9% and 9.6% of these DALYs, respectively. In terms of premature mortality, mental and substance use disorders accounted for 8.6 million years of life lost (YLL) or the equivalent of 232 000 deaths globally in 2010; and almost all of these deaths (81.1%) were attributable to SUDs (Whiteford, et al., 2013). Substance use is increasing worldwide, and the overall proportion of people using opiates, cocaine, and cannabis rose by 34.5%, 27%, and 8.5% respectively, between 1998 and 2008 (Global Commission of Drug Policy, 2011).

In Canada, more individuals will experience SUDs than mood disorders in their lifetime (Government of Canada, 2013). In 2012, approximately 21.6% or 6 million Canadians aged 15 years or older, met criteria for lifetime experience of a SUD, and 4.4% met criteria for an SUD in the past 12 months (Government of Canada, 2013). SM also accounts for a significant amount of Canadian morbidity and mortality. Patra et al. (2007) reported that in 2002, use of alcohol, tobacco, and illicit drugs resulted in over 4 million (10.8%) acute care hospital days and 772 925 potential years of life lost, or 16.6% of all premature mortality. Furthermore, 20.3% of Canadian deaths occurring under age 70 were attributable to SM in 2002 (Patra et al., 2007). Beyond significant burden of disease, SM is associated with high economic costs resulting from lost productivity, along with health, social, and law enforcement

expenditures. In the United States alone, it is estimated that SM costs $366 billion dollars annually (National Institute on Drug Abuse, 2008), while in Canada, the economic impact of SM was estimated to be $39.8 billion, or $1267 per capita, in 2002 (Canadian Centre on Substance Abuse, 2006).

Demographic correlates of substance use disorders

SM and SUDs are most common amongst males and younger people (Stone, et al., 2012 Whiteford, et al., 2013; Compton, et al., 2005). The global burden of disease is greatest amongst those aged 15-29 and 25-49 respectively, and males experience a greater burden of disease than females in all age groups (Whiteford, et al., 2013). These patterns are also evident in Canada, where prevalence of past-year SUDs is highest amongst youth aged 15 to 24 (11.9%) and lowest among adults aged 45 and older (1.9%). Additionally, males have higher rates of past-year alcohol (4.7% vs. 1.7%) and cannabis use disorders (1.9% vs. 0.7%) than females, but similar rates of other drug use disorders (0.9% vs. 0.5%) (Government of Canada, 2013).

Beyond sex and age, in Canada, indigenous (First Nations, Inuit, and Métis) people experience a disproportionate amount of harm from substance use relative to other members of the general population. Despite having a higher proportion of abstainers, the rate of alcohol-attributable mortality amongst indigenous people is almost double the rate for the general population. Additionally, the rate of illicit drug-attributable mortality is about three times higher than in the general population (Reading, & Halseth, 2013). Although indigenous people comprise only 3.8% of the Canadian population, they accounted for 8% of all people living with HIV and 12.5% of all new HIV cases in 2008 (Public Health Agency of Canada, 2010). The majority (66%) of these new cases were attributable to injection drug use. Rates of injection drug use-driven HIV infection are especially high in Saskatchewan, where indigenous people living on reserve have an HIV incidence rate (63.6 per 100,000) eleven times the national average (5.9 per 100,000) (Leo, 2015).

It should be noted that there is nothing inherent about having indigenous ancestry that puts

people at greater risk for SM or SUDs. Rather, disproportionate rates of SUDs and related harm amongst indigenous people reflect the consequences of European colonization, cultural genocide perpetrated through the residential school system, contemporary systemic and systematic discrimination, and the ongoing socioeconomic marginalization of this population across Canada (Reading & Halseth, 2013; Frohlich et al., 2006; Fine, 2015; Truth and Reconciliation Commission of Canada, 2015).

Substance use disorders and socioeconomic marginalization

Although SUDs occur across the socioeconomic spectrum (Kendler, et al., 1997), a large body of international evidence indicates that they are particularly common among people who are socioeconomically marginalized, and that SUDs are both precipitated and exacerbated by exposure to adverse socioeconomic conditions (Galea, & Vlahov, 2002; Boardman, et al., 2001; Wilkinson, & Marmot, 2003; Room, 2005; Brook, et al., 2008).

Brook et al. (2008) identify a number of ways that socioeconomic marginalization can increase risk of SUDs, including: (1) experience of environmental stressors associated with residing in an impoverished neighbourhood; (2) increased proximity to illicit drug markets and social networks of people who use drugs; (3) experiences of multiple adverse life events; and (4) recurrent experience of stigma and/or discrimination. Additionally, people with lower socioeconomic status are less likely to benefit from access to quality housing and nutrition, effective health care, social supports, and social capital—protective factors that can reduce risk of SM, prevent development of more severe disorders, and increase the effectiveness of substance use treatment (Canadian Centre on Substance Abuse, 2014).

The relationship between SUDs and socioeconomic marginalization appears to be bidirectional. While socioeconomic marginalization increases the risk of experiencing an SUD, SM and/or an SUD can also lead to declining socioeconomic position. Individuals whose SUD goes untreated may experience increased difficulty responding effectively to daily tasks and challenges (Raphael, 2009; Canadian Centre on Substance Abuse, 2014), and there is evidence that people struggling with SUDs are more likely to

experience greater absenteeism, lost productivity, and/or work-related injuries resulting in increased vocational instability or unemployment (Brook, et al., 2008). For people who use illicit drugs (PWUD), these risks may be compounded by criminalization and the long-term impacts of a conviction on employment prospects (Erickson, & Hyshka, 2010; Alexander, 2010). Moreover, in many jurisdictions an SUD is not recognized as an eligible condition for public disability benefits, and/or evidence of substance use may result in loss of income support or other social entitlements normally available to low income individuals (Swartz, et al., 2000; Anderson, et al., 2002; Dohan, et al., 2005).

The significance of the relationship between socioeconomic marginalization and SUDs is perhaps most evident in the high prevalence and burden of disease amongst homeless and/or street-involved populations (Fazel, et al., 2008; Fischer, et al., 2005; Galea, & Vlahov, 2002; Palepu, et al., 2013; Argintaru, et al., 2013; DeBeck, et al., 2011). Compared to other low income individuals in the general population, homeless and/or street-involved people experience higher rates of mental health problems and SUDs (Palepu, et al., 2013; Hwang, 2001; Boivin, et al., 2005; Topp, et al., 2010). A systematic review of mental health and SUDs amongst homeless populations in North America, Western Europe, Australia, and New Zealand estimated the overall prevalence of alcohol and drug use disorders at 37.9% and 24.4% respectively (Fazel, et al., 2008). Similar rates have been observed amongst homeless and street-involved populations in Canada. Palepu and colleagues (2013) surveyed 1191 homeless and vulnerably housed persons in Vancouver, Toronto, and Ottawa and found that over half (53%) of participants met clinical criteria for a drug use disorder and more than one third (38%) met criteria for an alcohol use disorder.

Injection drug use among homeless and/or street-involved populations, in particular, has attracted significant attention from law enforcement, health professionals, policymakers, and researchers over the past two decades (Mathers, et al., 2008; Des Jarlais, et al., 1996; Mathers, et al., 2010). This is in part because injection is one of the riskiest routes of drug administration, and is

associated with elevated rates of overdose morbidity and mortality, HIV and HCV infection, cutaneous and sub-cutaneous abscesses, endocarditis, talcosis, and a host of other negative health outcomes (Degenhardt & Hall, 2012; Galea, & Vlahov, 2002). A number of specific risk behaviours increase the likelihood of these negative health outcomes amongst people who inject drugs (PWID), including: syringe sharing, injecting in public locations, injection equipment reuse, injecting alone, etc. These behaviours are particularly common amongst street-involved or homeless people, who often lack access to sterile supplies or safe places to inject, and are more likely to rush while injecting in public out of fear of victimization or police detection (Corneil, et al., 2006; Rhodes, et al., 2006; Kerr, et al., 2007). In Canada, cohort studies of street-involved PWUD have reported HIV prevalence rates as high as 29% (Spittal, et al., 2003; Strathdee, et al., 1997) and HCV prevalence rates as high as 82% (Patrick, et al., 2001). However, to date the majority of this literature has focused on understanding blood borne pathogens and related health services utilization amongst street-involved and/or homeless PWUD. Relatively few studies of PWID have examined (1) rates of substance use and other mental health disorders, (2) mental health and substance use service utilization, or (3) barriers to access to substance use services and supports amongst these populations.

Societal responses to substance use disorders

Given the high individual and population burden of SM and SUDs, a number of different approaches have evolved historically in an attempt to mitigate health, economic, and social costs (Reinarman, et al., 2015). These approaches are predicated on different understandings of substance use and often reflect broader intellectual, social, and political trends. As a result, conflicting perspectives have been used to both understand the causes of SUDs and to prescribe solutions for ameliorating them and their related harms (Reinarman, et al., 2015). In Canada and other high income countries, three dominant responses to SM and SUDs are to ascribe them to: (1) moral failing, (2) illness or disease, or (3) the social environment. Each of these perspectives implies a range of solutions including criminalization,

treatment, harm reduction, or various socioeconomic and political reforms (Rhodes, 2009; Babor, et al., 2010).

Moral response

From this perspective, SM is a form of deviant behaviour. It follows that social reactions to deviance legitimately involve formal or informal sanctions designed to discourage socially harmful patterns of alcohol and other drug use, and to reinforce sociocultural mores regarding legitimate versus illegitimate uses of psychoactive substances (Carstairs, 2006). Proponents of the moral perspective view people experiencing SUDs as having made 'bad choices' which need to be corrected through criminal (or other) sanctions, and other interventions (Giffen, et al., 1991). Some examples of interventions endorsed by a moral perspective include: criminal penalties for drunk driving; arrests or fines for public alcohol consumption or intoxication; tobacco 'denormalization' campaigns; in-school D.A.R.E. (Drugs Abuse Resistance Education) programs; and criminalization of illicit drug possession and trafficking. In most jurisdictions, moral perspectives dominate debates about how society should respond to SM, and a large proportion of the resources devoted to addressing SM are spent on law enforcement and the criminal justice system (Room, 2005; Babor, et al., 2010; Anthony, et al., 2005). For example, it has been estimated that, internationally, law enforcement expenditures related to illicit drug use alone top $100 billion annually (Rolles, et al., 2012); and in Canada, law enforcement accounted for $5.4 billion of all costs related to substance use in 2002 (Rehm, et al., 2006).

Medical response

Medical perspectives on substance use developed prior to the 20th century, but became increasingly more dominant in public and policymaker discourses in North America and elsewhere during the late 1990s (Hall, et al., 2015; Reinarman and Granfield 2015; Courtwright, 2015). Originally advanced by Jellinek (1960) and the founders of Alcoholics Anonymous (Keller, 1976), these perspectives have further developed through animal model and functional neuroimaging studies, which

advance a disease model that views SUDs as the product of a chronic, relapsing brain disorder. The disorder is characterized by compulsive drug seeking and use behaviour, despite the experience of negative personal and social consequences (Leshner, 1997; Volkow, & Li, 2004). Under the modern disease concept, people with moderate to severe SUDs are believed to suffer from pervasive changes in brain structure and function brought on by prolonged drug use, which may persist long after drug taking has been discontinued (Leshner, 1997). These changes are thought to represent a "high-jacking" of the brain's mesolimbic reward system, impairing an individual's ability to make rational decisions and exercise impulse control (Hall, et al., 2015). Proponents of the medical perspective on SUDs argue that pharmacological and psychosocial treatments are required to help individuals reverse or compensate for structural and functional brain changes, and achieve abstinence or control over drug use behaviour (Hall, et al., 2015). Examples of these interventions include: methadone, buprenorphine or other opioid dependence therapies; naltrexone and other antagonists that block the pleasurable effects associated with consuming alcohol or opiates; cognitive behavioural therapies; and relapse prevention, contingency management, as well as exposure to self-help and peer support groups.

Social response

The social response perspective on SUDs emphasizes the social patterning of SM and the significant impact that micro, meso, and macro level social environments have on drug use patterns and experiences of substance-related harm (Alexander, 2008; Rhodes, et al., 2005; Alexander, 2012; Rhodes, 2002; Rhodes, 2009; Bourgois, 2000; Bourgois, 2003). Proponents of this approach are mainly academics working in the areas of political economy, social epidemiology, social psychology, or sociology; harm reduction services providers; or people with lived experience of substance use and structural disadvantage (Rhodes, 2009). Proponents emphasize the importance of social context for both shaping individuals' decisions to use drugs, and developing appropriate intervention approaches for SM. This perspective attempts to shift the responsibility for SM, SUDs, and related harm "from individuals alone

to include the social and political institutions, which have a role to play in harm production" (Rhodes, 2009, p. 193). On this view, then, causal pathways to SM or SUD reflect a complex interplay between individual agency and structural forces, which both shape and constrain behaviour. Overemphasis on individual risk reduction or recovery from SUDs is seen as victim-blaming, because it puts the onus on the individual to protect his/her own health without recognizing larger socioecological factors that exacerbate harm and produce structural vulnerability to SUDs (Rhodes, 2002). Instead, proponents of social responses to SM seek to decrease health inequities experienced by people living with SM and SUDs through political advocacy, destigmatization, and empowerment efforts. Some examples of proposed solutions under this perspective include: interventions to reduce income inequality and health inequities; affordable housing; harm reduction strategies to reduce collective and individual risk of harm from alcohol, tobacco, and illicit drugs; peer outreach and advocacy; and ending the criminalization of people who use illicit psychoactive substances.

Importantly, the three perspectives articulated above are neither exhaustive nor mutually exclusive. For example, many police forces collaborate with mental health and substance use professionals to improve access to care for individuals experiencing SUDs (Butler, 2014); many addiction medicine specialists acknowledge the importance of environmental and social factors in contributing to development of SUDs (Leshner, 1997; Volkow, et al., 2003); and proponents of social environmental perspectives on SM typically do not deny the physiological impacts of dependence and withdrawal that manifest as SUDs, nor the benefits of pharmacotherapy and other individual-level interventions for PWUD (Bourgois, 2000; Degenhardt, et al., 2010). In reality, these perspectives overlap to some extent and many working in the area of substance use ascribe to various aspects of each.

A public health response to substance use

Over the past decade, researchers, health professionals, and peer advocates have attempted to theoretically and practically unify various aspects of the moral, medical, and social perspectives under a

public health framework for preventing and mitigating harm associated with SM (Health Canada & Canadian Centre on Substance Abuse, 2005; Health Officers Council of British Columbia, 2005, 2011; Canadian Public Health Association, 2014; Canadian Public Health Association, 2011; Babor, et al., 2010; Pacula, et al., 2014; Haden, & Emerson, 2014; Carter, & MacPherson, 2013). A public health approach to tobacco, alcohol, and illicit drugs incorporates social justice principles; attention to human rights and equity; evidence-informed policy and practice; and knowledge of the underlying biological, psychological, and social determinants of health to reduce prevalence of SM and SUDs rather than all use *per se* (Canadian Public Health Association, 2014). The public health response differs from previous responses, because it emphasizes understanding and mitigating the negative health impacts of SM and SUDs at a *population level*, i.e. achieving aggregate reductions in morbidity and mortality, and not just positive social or clinical outcomes for individuals. Rather than only focusing on clinical interventions for treating individuals who exhibit SUDs, or sanctioning those who exhibit problematic patterns of use, this approach aims to reduce the overall contribution of SM to poor population health outcomes and prevent various population groups from experiencing disproportionate levels of substance-related harms. The public health response, therefore, applies systems-thinking (i.e. examining the linkages and interactions between various substance use service system components and broader social and economic environments) to understand how health policies, interventions, and service systems can work together to reduce the overall burden of disease associated with SM and SUDs in a given jurisdiction.

A public health response recognizes that "psychoactive substances, as well as the interventions designed to deal with them, have both benefits and harms" and aims to strike an appropriate system of regulated access that "achieve[s] a reasonable balance between the benefits and the harms of both the substances and their regulation" (Health Officers Council of British Columbia, 201, pg. 5). It adopts a four-pillar approach to substance use that incorporates enforcement, prevention, treatment, and harm

reduction responses, and endorses interventions like drug depenalization (e.g., removal or reduction of criminal sanctions) and universal school-based prevention programs. To these are added equitable access to coordinated systems of evidence-based services and supports in general health care including: screening, brief intervention, and referral to treatment (SBIRT) programs that often provided in primary care; and emergency and acute care provided in hospital settings. Additionally, the public health response recognizes the role of evidence-based specialist addiction treatment services, including information and intake assessment; social or medical withdrawal management; outpatient treatment; short-term and long term inpatient treatment, often in residential settings; counselling; pharmacotherapy (methadone, naltrexone, buprenorphine, diacetylmorphine, etc.); aftercare; recovery monitoring; social services; managed alcohol programs; syringe and injection-equipment distribution; supervised consumption services; street outreach; safer inhalation programs; and 'safe dance' initiatives. This array of services is designed to meet the diversity of needs that exist across populations exhibiting SM, again with the overall goal of improving health, social, and economic outcomes at the population level.

To date in North America, the majority of efforts devoted to developing a public health response to substance use have focused on promoting regulatory, policy, and legal changes to decrease the population burden of tobacco, alcohol, and illicit drug misuse. However, some public health researchers and experts have also brought systems analysis, health services research, and population health perspectives to bear on substance use service systems (Rush, et al., 2014; Babor, et al., 2008; Wild, et al., 2014). The next section outlines this work.

Public health perspectives on substance use service systems

A large international body of literature has described the variety of existing services and supports designed to treat SUDs and/or prevent related harm. An overriding conclusion of this research is that 'treatment works', with many services and supports producing reductions in substance use and

improving health and social outcomes for patients (Babor, et al., 2008; Strang, et al., 2012). Treatment services with the strongest evidence base include SBIRT interventions, opioid dependence therapy (methadone or buprenorphine treatment), and psychosocial treatment modalities (e.g., cognitive behavioural therapy, motivational interviewing, structured relapse prevention) (Strang, et al., 2012; Brown, et al., 2005; Selby, & Kahan, 2011). Additionally, a variety of harm reduction services including managed alcohol programs, syringe and injection-equipment distribution, street outreach, and supervised consumption services have been demonstrated to be effective in connecting people experiencing SUD to health and social services, thereby reducing negative health outcomes (Strang, et al., 2012; Ritter, & Cameron, 2006; Kimber, et al., 2010; Podymow, et al., 2006; Stockwell, et al., 2013). However, the vast majority of research on treatment and other substance use interventions has focused on their effectiveness at the individual-level. Relatively little research has examined the population health impacts of substance use services and supports, or evaluated service systems' abilities to reduce overall demand and achieve aggregate reductions in disease burden (Babor, et al., 2008; Mathers, et al., 2010).

The treatment gap

Existing research that investigates whether treatment systems are meeting the needs of populations demonstrates the existence of a large treatment gap. Despite increasing investments in the provision of evidence-based substance use services and treatments over the past half-century (Babor, et al., 2008), an alarming proportion of people experiencing SUDs or SM do not receive any services for these problems (Kohn, et al., 2004). Specifically, international data from several large population-based surveys find that even after accounting for illness severity, 35-50% of individuals meeting criteria for mental and substance use disorders do not access health or social services for these problems (WHO World Mental Health Survey Consortium, 2004; Bijl, et al., 2003 Urbanoski, et al., 2008). Additionally, global coverage of harm reduction services is far below optimal levels for preventing HIV-related burden

of disease, other morbidity, and mortality (Mathers, et al., 2010). The international experience is mirrored in Canada: 4.4% of Canadians met criteria for past-year SUD in 2012, but only 0.4% of the population accessed publicly funded treatment services that same year (Pirie, et al., 2014). Other services and supports for people with SUDs also have poor coverage rates (Carter, & MacPherson, 2013), and data from the 2012 Canadian Community Health Survey indicate that approximately 40% of Canadians, who have a need for mental health or SUD-related care, do not have their needs fully met (Sunderland, & Findlay, 2013). Addressing this 'treatment gap' and increasing uptake into substance use services and supports is becoming a particularly important objective for public health efforts in Canada and elsewhere (Health Canada, & Canadian Centre on Substance Abuse, 2005; Pirie, et al., 2014; Canadian Public Health Association, 2014; Canadian Public Health Association, 2011; Saxena, 2012; Ritter, 2013; Babor, 2015).

Growing recognition of this large, ubiquitous treatment gap has stimulated research on substance use service systems, with the intention of informing policymakers and program administrators about the best ways to reconfigure or expand substance use services to better meet population needs (Babor, 2015). In particular, growing prominence of a public health approach to SUDs has stimulated conceptual, theoretical, and empirical work on substance use service systems (Babor, 2015; Minoletti, et al., 2012; Babor, et al., 2008; Bergmark, 2010; Room, 2010; Holder, 2010; Rush, et al., 2014; Rush, 2010; Wild, et al., 2014; Ritter, 2013). This research has highlighted a number of current planning challenges that limit the potential of substance use service systems to meet population need and reduce burden of disease (Rush, 2010; Minoletti, et al., 2012; Babor, et al., 2008; Babor, et al., 2010; Babor, 2015; National Treatment Strategy Working Group, 2008). These challenges are outlined below.

Planning systems of substance use services and supports to meet population needs requires strategies, time frames, indicators, targets, and resource allocations all tailored to meet discrete objectives (Minoletti, & Funk, 2005). In Canada and many other jurisdictions, these decisions have

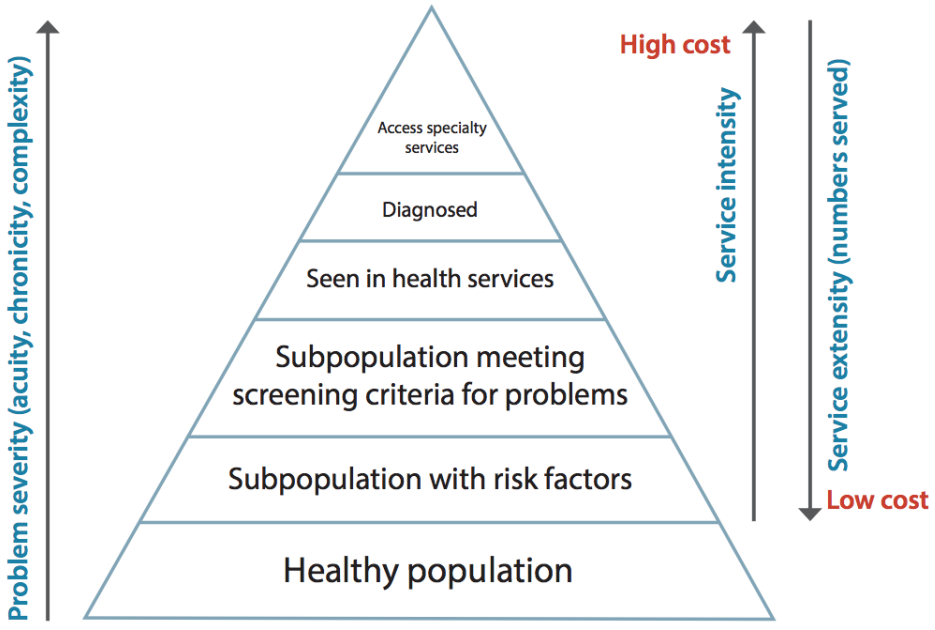
historically been made through a *normative service planning approach* (Pirkis, et al., 2007 Wild, et al., 2014 Rush, et al., 2014). This approach emphasizes stakeholder consultation, political advocacy, and changing funding priorities as the main bases for determining which substance use services to offer in a given time period or funding cycle (Rush, et al., 2014). Additionally, levels of service provision in jurisdictions perceived to be addressing SM 'well,' are often applied as proxies for planning in other regions without consideration of regional variability in population characteristics, or extant levels of need and demand (Wild, et al., 2014).

Across many Canadian jurisdictions, using a normative system planning approach has resulted in haphazard and fragmented services, with programs and supports being delivered through a patchwork of clinics, hospitals, community agencies, and private or contracted service providers. These services tend to be poorly funded, and because annual funding allocations are often based on the dollar amounts allotted in the previous year, gaps between population need and treatment capacity tend to be replicated year-over-year (Rush, et al., 2014; Carter, & MacPherson, 2013). Normative service planning approaches have also contributed to an over-emphasis on maintaining existing programs and services within particular parts of health systems, rather than integrating efforts across service settings. Most substance use services and supports are not well coordinated, and tend to be implemented primarily in specialized service settings, rather than integrated within general health and social service settings (e.g., emergency departments, physicians' offices, or social service agencies) where many people experiencing a SUD are likely to present for care (Rush, et al., 2014; National Treatment Strategy Working Group, 2008). As a result, the majority of resources allocated to substance use services and supports are spent on services designed specifically for people with the most severe and complex needs, such as specialized in-patient rehabilitation programs (National Treatment Strategy Working Group, 2008; Rush, et al., 2014). This is problematic because large proportions of the population of people experiencing substance-related harm and/or SUDs do not require such highly specialized and costly care (Rush, et al.,

2014).

The public health response to SM and SUDs uses population health pyramids to understand this dilemma (Rush, et al., 2014; Wild, et al., 2014). As with other chronic health problems, burden of disease is not equally distributed amongst the population of people exhibiting SM and SUDs. Rather, this distribution takes the shape of a pyramid (Figure 1-1), with the smallest number of people comprising the most severe cases—those with the highest degrees of chronicity, acuity, and complexity—concentrated at the top. Larger numbers of less severe cases comprise the middle of the pyramid, with an even greater number of individuals at the base. Individuals at the base are experiencing significantly less risk and harm than those above them and are mainly targets for primary and secondary prevention interventions (Rush, et al., 2014; Wild, et al., 2014). Overall, service intensity and cost should increase as severity increases, and for the system to be effective, members of the population should receive the least intensive and expensive services able to satisfy their needs.

Figure 1-1. Problem severity in relation to population size, service intensity/extensity, and costs (source: Wild, et al., 2014)



Substance use service systems are unlikely to achieve discernible population-level decreases in

rates of SUDs or related morbidity and mortality if supports and services are mainly tailored to the relatively small number of individuals who comprise the most complex and severe cases (Rush, et al., 2014; Babor, et al., 2008; Ritter, 2013). A broader population health approach is needed; one that engages a wider set of health and social service settings and provides a comprehensive array of services and supports designed to meet the needs of all people at risk of or experiencing an SUD and related harm (Rush, et al., 2014; Babor, 2015; Ritter, 2013;).

Tiered frameworks for substance use service system planning

Increasing recognition that a diversity of need for substance use services exists across the population has led to the development of new approaches, which emphasize the importance of problem severity for service system planning. Rather than taking a normative systems planning approach, these efforts take a *'needs-based' planning approach* to align service systems with varying levels of need for substance use services and supports found in a given population (Rush, et al., 2014: Babor, 2015; Ritter, 2013). One particularly influential needs-based planning approach has been the continuum-of-care model. This model views substance use problem severity as a continuum and organizes the provision of services so that structure and intensity increase along with higher degrees of patient severity (Rush, et al., 2014; Babor, 2015; Rush, 2010; Rush et al., 2010). The continuum-of-care model is used widely today, including in the American Society of Addiction Medicine's criteria for patient treatment placement (Mee-Lee, 2013). However, this approach has been criticized as focusing too heavily on specialized care settings (e.g., withdrawal management, rehabilitation programs, acute mental health facilities, long term residential supports, aftercare, counselling, etc.) and does not include many other general health and social settings where people experiencing SUDs are most likely to present for care (Rush, et al., 2014).

Tiered planning frameworks are another approach to needs-based planning. These address shortcomings of the continuum-of-care approach by explicitly addressing lower levels of problem

severity in the population and 'broadening the base' of substance use services and supports to include general health and social services settings (Rush, 2010; Rush, et al., 2014; Institute of Medicine, et al., 1990; Babor, 2015; National Treatment Strategy Working Group, 2008). Tiered frameworks are based on the chronic care model for long-term health problems and coordinate services over time. They operate under the assumption that once SM or an SUD has developed, there is a need for continuing care and management, as is routinely done with other chronic conditions like diabetes or hypertension (Babor, 2015, pg. 1216). Tiered frameworks have been used as aides to substance use service system planning in the UK, Australia, Europe, and Canada (Rush, 2010; Rush, et al., 2014; Babor, 2015; Ritter, 2013).

Figure 1-2. Rush's tiered framework for substance use service planning (source: Rush, et al. 2014).

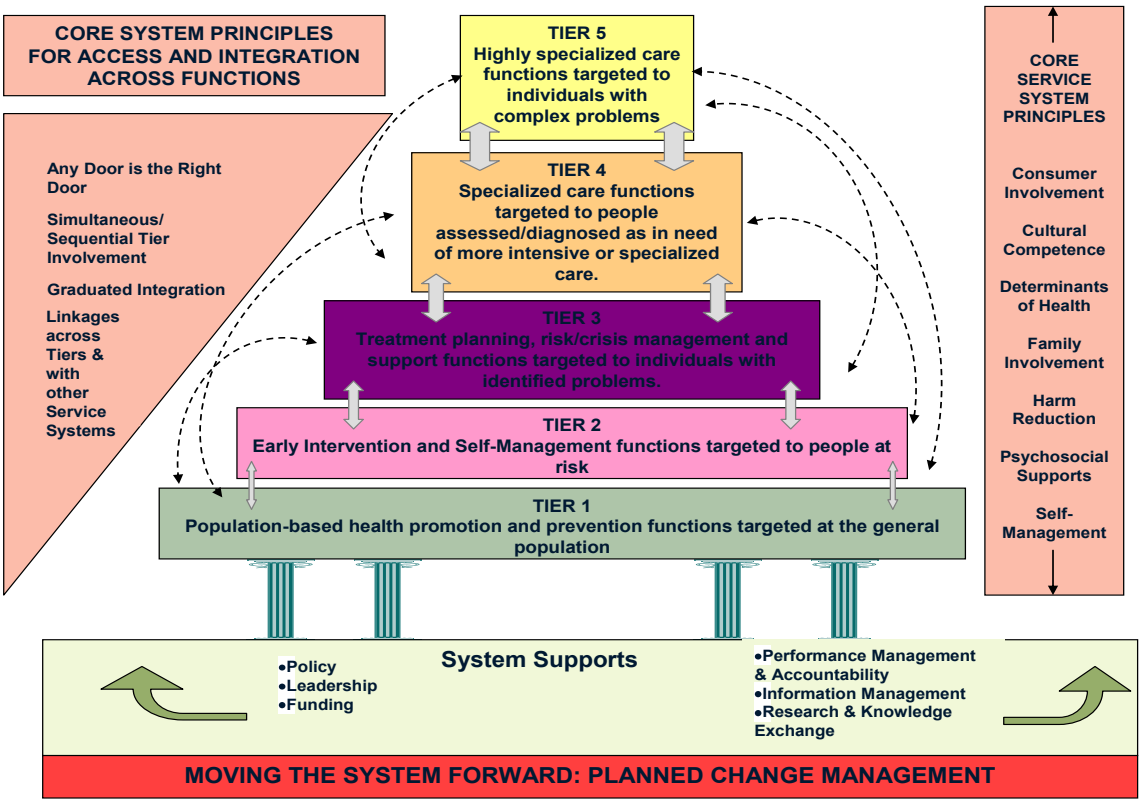


Figure 1-2 outlines one example of a tiered framework for substance use service system planning. Developed by Rush (2010, 2014) and endorsed by the Canadian Centre on Substance Abuse, this framework specifies a series of five service tiers on the basis of the 'functions' they provide. Rush et

al. (2014) define a function as a “higher-order group of like services or interventions aimed at achieving similar outcomes and targeted at a particular level of problem severity” (p.8). Additionally, “since a range of functions from more than one tier may be provided within one program/service, a function is thereby distinguished from the program or service in which it is embedded (e.g., needle exchange program, community mental health agency, emergency department, etc.)" (Rush, et al., 2014, pg. 8-9). Functions are grouped into ascending tiers based on the increasing degree of specialization (e.g., general health promotion to in-patient care) and skilled competency required.

Beyond an arrangement of service functions that corresponds to increasing levels of service, specialization, structure, and intensity, Rush’s tiered framework emphasizes a series of core principles that facilitate the movement of individuals and patients throughout substance use service systems (Rush, et al., 2014). First, ‘every door is the right door’; ideally, people access the system through any of the five tiers and are then linked to other functions within or across tiers as appropriate to their needs. No one program or facility ‘owns’ the presenting individual, rather the individual becomes the client of the whole system. Second, any given program or setting can provide multiple functions across multiple tiers. Third, the system is arranged in a way that facilitates coordination and continuity across different functions, tiers, and settings (Rush, et al., 2014).

Taken together, tiered frameworks and their organizing principles are intended as a “planning tool to guide the development and implementation of an integrated system of service functions” for people at risk of, or experiencing, substance use problems. They are devised to provide a broader “vision of a comprehensive, integrated system, based on an alignment of service functions with the level of severity in the population” and as such, have the potential to significantly improve substance use service systems, narrow the treatment gap, and decrease substance use related morbidity and mortality at a population-level (Rush, et al., 2014, pg. 12).

From a public health perspective, moving away from normative planning approaches towards

needs-based planning approaches that systematically match varying levels of population need to appropriate kinds of services and supports requires routine collection and analysis of high quality population data on: (1) the number of people in need of substance use services; (2) varying levels of problem severity in the population; and (3) service needs as they relate to severity (Rush, et al., 2014; Babor, 2015). The next section reviews methods for assessing population need for substance use services and considers their utility for informing needs-based service planning.

Assessing population need for SM services

Recognition of the large substance use disorder treatment gap, and calls for better evidence to inform substance use service planning, have led to a growing interest in estimating population need for substance use services in relation to actual service coverage (Institute of Medicine Committee for the Study of Treatment and Rehabilitation Services for Alcoholism and Alcohol Abuse, & National Institute on Alcohol Abuse and Alcoholism, 1990; Rush, 2010; Mechanic, 2003). This reflects a shift away from research characterizing the demographic and clinical correlates of treatment-seekers toward community-based, public health studies of need for services in both general and special populations, regardless of whether general health care or specialty addiction treatment was actually sought or received (Horwitz & Grob, 2011). These efforts have been multidisciplinary, with clinicians and scientists from psychiatric epidemiology, psychosocial, and health services research traditions all contributing to the literature on population need to substance use services.

Conceptualizing population need for substance use services

Given the inherent disciplinary diversity associated with measuring population need, it is unsurprising that a variety of definitions of 'need' have been proposed to facilitate conceptualization and measurement (Aoun, et al., 2004; Rush, et al., 2014). One early attempt was Bradshaw's (1972) taxonomy of social need (Aoun, et al., 2004; Rush, et al., 2014). He defined four types of need, including

normative need, expressed need, felt need, and comparative need. *Normative* need is expert-determined and typically measured through structured survey interviews that employ clinical screening or diagnostic instruments. *Expressed need* reflects objective demand for services and may be estimated using surveys that assess self-reported service utilization or through analysis of health administrative data. *Felt need* is based on an individual's own perception of the problems he/she has and/or the services he/she requires. It can be measured using survey methods that ask alcohol and drug users about their perceptions of their own need for help or services. Finally, *comparative need* is assessed by evaluating the needs of one population relative to the needs of another population or group (e.g., males versus females) (Bradshaw, 1972). Though terminology has changed, these definitions are still evident in current scholarship on population need for substance use and mental health services.

Contemporary approaches used to assess different types of need for substance use services at the population level can be divided into two main categories: indirect estimation techniques and direct estimation through population surveys (Aoun, et al., 2004; Crook, & Oei, 1998; Dewit, & Rush, 1996; Aoun, et al., 2004; Minoletti, et al., 2012; Joska, & Flisher, 2005).

Indirect estimation techniques

Initial approaches to measuring population need for substance use services relied on indirect estimation techniques designed to quantify need for services in relation to the prevalence of substance use, and SM in the general population (Crook & Oei, 1998; Dewit & Rush, 1996; Fiorentine, 1994; Ford, 1985). Because these techniques and their underlying assumptions, strengths, and limitations have been thoroughly described elsewhere (Crooke & Oei, 1998; Dewit, & Rush, 1996; Fiorentine, 1984; Ford, 1985), I will only briefly review these approaches here. In many jurisdictions, estimating population need for substance use services directly is cost-prohibitive. As such, researchers developed a number of statistical models to gauge population need for services indirectly. These models "make use of existing naturalistic or historical data" (e.g., retail alcohol sales, mortality data, HIV testing databases) when

representative data from direct contact self-reports (e.g., obtained through general population needs assessment surveys) are unavailable or too difficult to obtain (Dewit, & Rush, 1996, pg. 41). Common indirect need estimation techniques include: the capture-recapture model, the Poisson distribution, synthetic estimation techniques, the Ledermann model, mortality-based prevalence models, the drug acquisition curve, normative models, and prescriptive models (Dewit, & Rush, 1996; Crook & Oei).

These models incorporate a large variety of data sources and underlying assumptions. For example, the *capture-recapture* and *Poisson distribution* techniques both attempt to estimate the size of a population of illicit drug users based on existing inventories of people who use drugs (e.g., lists of individuals incarcerated on drug charges or in drug treatment) or the frequency of certain events (e.g., drug arrests) in a given jurisdiction. The *synthetic estimation technique* takes readily obtainable information on sociodemographic correlates (e.g., age, gender, marital status, ethnicity) and other indicators of substance use from a 'calibration' population (e.g., people seeking treatment) in which drug use can be directly measured. It then uses this information to develop estimates of need for populations where levels of drug use are unknown. The technique may include combining national-level population survey data with local census data to yield 'small area' estimates of drug use or extracting socio-demographic indicators associated with alcohol-related problems from census data to estimate expected prevalence of alcohol use disorders in a given population.

In contrast, the *Ledermann model* assumes that in the general population, a fixed proportion of people who drink experience alcohol use disorders; it employs mean alcohol consumption rates at the population level (obtained from alcohol sales or taxation data) to estimate the prevalence of heavy drinking. *Mortality-based prevalence models* take estimates of deaths from liver cirrhosis or suicides to estimate the total number of people who experience alcohol use disorders in a given region. The *drug acquisition curve* relies on the finding that early adolescent substance use is the best predictor of substance use problems in adulthood. It uses estimates from retrospective self-report data to predict

the proportion of adolescents who will have used drugs or alcohol at every age, and the number of people who will experience substance use problems in their lifetime (Dewit, & Rush, 1996).

Normative models are demand-based, and measure current treatment needs based on past patterns of service utilization and service system capacity. These models estimate the total number of expected clients and required treatment capacity in a given jurisdiction through a combination of existing data on need indicators (e.g., in the case of alcohol: mortality rates from liver cirrhosis and alcohol poisoning) and rates of help-seeking derived from treatment system data. Finally, *prescriptive models* incorporate prevalence estimates of the size of the population in need of services as a basis for determining treatment capacity, rather than focusing on existing capacity as means to predict service use. Prescriptive models assume that not all people requiring treatment will seek it and that limited resources constrain treatment supply. Based on these assumptions and assumed rates of relapse, incidence, and population growth, the models estimate the proportion (usually around 20 percent) of people experiencing alcohol use disorders, who 'ought to' access treatment in a given year (Dewit, & Rush, 1996).

The indirect estimation techniques outlined above offer system planners a number of advantages. They are typically based on analysis of easily obtainable data and so provide a cost effective means to systematically estimate population need for substance use services (Crook, & Oei, 1998; Dewit, & Rush, 1996). This is especially important in resource-constrained government bureaucracies, where the funds necessary to collect primary data on population need may not be available. Additionally, several of these models are based on simple assumptions and equations that do not require advanced mathematical or statistical modelling capabilities (Dewit, & Rush, 1996).

However, a number of limitations exist in using indirect estimation techniques to understand population need for SM services. Most of these models are grounded in statistical and methodological assumptions, which are difficult to verify, and research comparing the relative validity and reliability of

two or more approaches is rare (Dewit, & Rush, 1996). As a result, it is difficult to know which modelling method might be a 'gold standard' for quantifying population need for SM services. Additionally, almost all of the models outlined above are appropriate for generating estimates of population need for *either* drug or alcohol-related substance use services only, not both. In-direct estimation techniques are rarely valid for both licit and illicit psychoactive substances (Dewit, & Rush, 1996). Finally, indirect estimation techniques have limited capacity to inform service system planning because they typically do not differentiate between subpopulations that might benefit from different types of services in relation to problem severity, e.g., substance misusers versus those meeting diagnostic criteria for substance use disorders; people who do and do not exhibit comorbid substance use and mental disorders. These limitations hinder efforts to estimate how many people in the general population could benefit from accessing the variety of treatment interventions and supports for substance misuse typically offered by general health care and speciality service systems (e.g., brief interventions, outpatient care, speciality residential treatment) (Dewit & Rush, 1996).

Direct estimation through population surveys

The shortcomings of the above indirect estimation techniques have resulted in a turn towards direct estimation methods using community-based population surveys. Population surveys have the ability to assess need for care amongst individuals who may or may not be in contact with services, measure problem severity, and more accurately gauge the size of a jurisdiction's SUD treatment gap. As such, the World Health Organization and other mental health authorities have indicated that when sufficient resources are available, primary data collected via population surveys are the preferred means for measuring need for care for SUDs and other mental health problems (Minoletti, & Funk, 2005; Minoletti, et al., 2012). Population-based, cross-sectional surveys measuring need for mental health and substance use care have now been conducted across the United States, Australia, Canada, and Europe. These surveys have also been administered in some low and middle-income countries including Brazil,

Chile, and Mexico (Kohn, et al., 2004; Minoletti, et al., 2012).

Direct estimation methods using population surveys attempt to quantify population need for services in relation to prevalence estimates of substance use, substance use service utilization and/or SUDs—as assessed by structured diagnostic instruments (e.g., the Composite International Diagnostic Interview [CIDI] (Horwitz & Grob, 2011; Kohn, Saxena, Levav, & Saraceno, 2004). The Epidemiological Catchment Area Program (ECA; 1980-1985) (Regier et al., 1993) and the first iteration of the National Co-Morbidity Study (NCS; 1990-1992) (Kessler et al., 1994) were two early examples of this approach. These seminal studies clearly documented that most people meeting diagnostic criteria for SUDs do not access health services. The ECA reported past year general health care and specialty treatment rates of 23.6% for respondents meeting diagnostic criteria for any SUD (Regier et al., 1993), and the NCS reported rates varying between 11.6% (alcohol abuse) to 46.8% (drug dependence) in the NCS (Narrow, Regier, Rae, Manderscheid, & Locke, 1993). Other countries, across Europe, Australia, and elsewhere, have since implemented large population-based mental health surveys and demonstrated similar results (Bijl et al., 2003; Kohn et al., 2004).

Expert versus consumer perspectives on population need for services

The near ubiquitous finding of a large treatment gap for substance use as well other mental health problems has led some to question the validity of the diagnostic systems used in survey studies measuring population service needs (Mechanic, 2003; Regier, 2003). Some hypothesized that disorder prevalence estimates were overstated, and not a reliable indication of actual need for care in the population (Mechanic, 2003; Horowitz & Grob, 2012). Many experts have emphasized that meeting criteria for a specific disorder is not the same as requiring care, and as such, disorder prevalence alone is insufficient for assessing population need for mental health and substance use services (Joska, & Flisher, 2005; Mechanic, 2003; Regier, 2003). Subsequently, a number of changes were made to the Diagnostic and Statistical Manual (DSM-IV) Fourth Edition and the CIDI to provide information to enhance

diagnoses, and improve ability to assess clinical significance, functional impairment, and disability (American Psychiatric Association, 2000; Kessler, 2000; Regier, 2003). These changes produced more conservative prevalence estimates (Regier, 2003), but they reflected a continued reliance on an **objective, expert-determined perspective** on population need for services. This emphasis has been questioned however, due to evidence that diagnostically-assessed need for care is not a strong predictor of actual service use (Demyttenaere et al., 2004; Kessler et al., 2005; Mechanic, 2003; Minoletti et al., 2012; Regier, 2003). For example, data collected across seven high-income countries show that 36 to 50 percent of those who meet criteria for severe substance use and mental disorders report no past year service use; and most individuals who report accessing care have either low-severity problems or do not meet objective, expert-determined diagnostic criteria (Demyttenaere et al., 2004).

These results suggest that objective need studies, which divide respondents according to diagnostic classification and other clinical correlates, cannot account for why so many people experiencing SUDs do not access care, nor why some individuals seek care for low-severity problems, or in the absence of a diagnosis altogether (Minoletti, et al., 2012). Estimates of objective need and problem severity, therefore, are an important starting point for understanding population need for substance use services, but when it comes to determining service use, they may be insufficient for predicting accurately how many people, and with what type of disorders, are going to demand various services (p. 214) (Minoletti, et al., 2012).

From a broader health system perspective, during the last half of the 20th century, the deinstitutionalization of mental health and substance use services occurred alongside the development of service delivery models framing patients as active participants in health care, and enabling shared decision-making based on patients' own sense of well-being (Tomes, 2006). These models imply that population need for care is a socially negotiated process and at least partially determined by consumer perceptions of need (Druss, 2007; Meadows, Harvey, Fossey, & Burgess, 2000; Slade, 1994). The

importance of **subjective, consumer-defined perspectives** on population need for services is further articulated in Andersen's (1995) influential model of healthcare utilization, which highlights numerous perceptual, attitudinal, predisposing, and enabling factors that influence decisions to seek care. These factors affect individual perceptions of health care needs, and these perceptions are theorized to be a proximal determinant of service use. From this perspective, assessing consumers' subjective views on service need is at least as critical as determining disorder prevalence rates for researchers attempting to quantify need for services in a given population, with the aim of informing service system planning (Druss, 2007; G. Meadows et al., 2000). Beyond perceived need, two related concepts–self-assessed barriers to care (Nelson & Park, 2006) and help seeking from friends or family members (potentially in lieu of formal service use) (Reavley, Yap, Wright, & Jorm, 2011) –have also been examined by studies adopting a subjective, consumer-based perspective.

Population survey research on subjective need for substance use services, has examined prevalence and correlates of perceived need (Katz, et al., 1997; Fassaert, et al., 2008; Mojtabai R, et al., 2002; Oleski, et al., 2010; Myers, et al., 2014; Meadows, & Burgess, 2009; Meadows, et al., 2002; Codony, et al., 2009; Meadows, & Bobevski, 2011; Urbanoski, et al., 2007; Mulvaney-Day, et al., 2012; Mojtabai, & Crum, 2013; Melchior, et al., 2014; Harris, et al., 2005; Wells, et al., 2001; Nelson, & Park, 2006; Chen, et al., 2013; Roll, et al., 2013), self-assessed barriers to substance use service use (Urbanoski, et al., 2008; Sareen, et al., 2007; Chen, et al., 2013; Mojtabai, et al., 2011; Oleski, et al., 2010; Ojeda, & Bergstresser, 2008; Hornblow, et al., 1990) and help-seeking from friends and family members (Lennings, Kenny, Nelson, 2006; Reavely, et al., 2011; Ullman, & Najdowski, 2010; Quinn, Stoové & Dietze, 2013).

This research demonstrates that amongst individuals who meet objective diagnostic criteria for SUDS, only about 10-30 percent actually perceive a need for care (Rush et al., 2010; Meadows & Burgess, 2009; Mojtabai & Crum, 2013; Mojtabai, Olfson, & Mechanic, 2002) and that perceiving a need

for care is a strong predictor of service use (Green-Hennessy, 2002). Individuals who perceive unmet care needs report high levels of disability and distress (Urbanoski, Cairney, Bassani, & Rush, 2008), which tend to improve once care needs are met (Meadows & Burgess, 2009). However, amongst those who access services, 5 - 21 percent still report that unmet service needs (Rush et al., 2010; Chen et al., 2013; Meadows & Burgess, 2009; Melchior, Prokofyeva, Younès, Surkan, & Martins, 2014; Urbanoski et al., 2008).

Perceived unmet need for care for SUDs is positively associated with socioeconomic marginalization (Ojeda, & Bergstresser, 2008; Joska, & Flisher, 2005; Bijl, & Ravelli, 2000; Roll, et al., 2013) and problem severity (Nelson, & Park, 2006; Ojeda, & Bergstresser, 2008; Rush, et al., 2010; Mojtabai, 2009; Chen, et al., 2013; Urbanoski, et al., 2008). Additionally, females (Nelson, & Park, 2006; Bijl, & Ravelli, 2000; Melchior, et al., 2014), younger adults (Nelson, & Park, 2006; Ojeda, & Bergstresser, 2008; Rush, et al., 2010; Mojtabai, 2009; Urbanoski, et al., 2008; Roll, et al., 2013), and some racial minority groups (Mojtabai, 2009; Wells, et al., 2001; Melchior, et al., 2014; Harris, et al., 2005) report higher rates of perceived unmet service needs.

Research on subjective, consumer-defined need for substance use services has further identified a number of potentially significant barriers to service use experienced by those reporting perceived unmet needs (Nelson, & Park, 2006; van Beljouw, et al., 2010; Rush, et al., 2010; Chen, et al., 2013; Mojtabai, & Crum, 2013; Urbanoski, et al., 2008; Sareen, et al., 2007; Mojtabai, 2009; Mojtabai, et al., 2011; Clement, et al., 2015; Ojeda, & Bergstresser, 2008; Oleski, et al., 2010). Motivational or attitudinal barriers —such as a desire to self-mange one's own symptoms —are the most common reasons for not accessing services amongst individuals reporting unmet care needs (Nelson, & Park, 2006; van Beljouw, et al., 2010; Rush, et al., 2010; Sareen, et al., 2007; Mojtabai, & Crum, 2013; Mojtabai, et al., 2011; Oleski, et al., 2010; Ojeda, & Bergstresser, 2008; Urbanoski, et al., 2008). Structural barriers related to costs or system access issues tend to be less frequently identified across populations and disorders, with

the exception of a few studies (Mojtabai, 2009; Chen, et al., 2013) from the United States, where access to health care is not universal and substance use services are typically provided by private, for-profit managed behavioural health care organizations. Finally, there is some evidence to suggest that at least for certain subpopulations (e.g., young people), help-seeking from family and friends may be preferable to formal service use (Reavley et al. 2011; Lennings, Kenny, & Nelson, 2006).

Incorporating subjective, consumer perspectives on need into substance use service system planning

To be useful for service system planning and ultimately improve population health outcomes, research measuring perceived need should incorporate these data into needs-based calculations estimating the required service system capacity to meet population need for substance use services (Rush, et al., 2015; Rush, et al., 2014; Babor, et al., 2015). Recent research has outlined two methods for converting estimates of perceived need for substance use services into forecasts of how many people would be expected to seek care across tiered frameworks of substance use service functions (Rush, et al., 2014; Ritter, 2013; Wild, et al., 2014). For example, in Canada, Rush et al. (2014) used population survey data to stratify respondents into five categories of need, which correspond to the five service tiers in their framework. Their five categories of need include: (1) abstainers to light-to-moderate drinkers and drug users; (2) heavy drug or alcohol users who do not meet criteria for SUDs; (3) people meeting criteria for a SUD *or* experiencing four or more substance-related problems; (4) people meeting criteria for a SUD or experiencing four or more substance related problems, *and* perceiving a need for care, reporting past-year service use, or assessed as experiencing significant interference from drugs or alcohol in one or more aspects of life; and (5) people who meet all criteria in category 4 *and* meet criteria for two or more comorbid mental health disorders, *and* experience significant interference from at least one of these disorders, *and* have a disabling physical or mental condition. These results were then used to model the required service capacity to meet population need across all five tiers of

substance use service functions. Ritter et al. (2013) adopted a similar system planning approach using perceived need data in Australia. They combined prevalence estimates of SUDs (by drug type, age group, and severity), with estimates of perceived need, and treatment demand, to determine the number of individuals who required specific bundles of substance use services (referred to as 'care packages'), and the amount of resources required to deliver this care and meet population need (Ritter, 2013).

The above synthesis of findings from population survey research on subjective need has outlined insights into unmet need for care for SM and SUDs that would not be available through findings from objective need studies alone. It also demonstrates the potential for using data on perceived need to inform service system planning. Accordingly, many have called for complementing objective, expert-derived approaches to direct estimation of population need with subjective, consumer-derived measures (Aoun et al., 2004; Minoletti et al., 2012; Ritter, 2013; Rush, et al., 2014), since they have the potential to enhance service planning and provide a more complete assessment of population need for substance use services (Ritter, 2013; Rush et al., 2014; Wild, Wolfe, Wang, & Ohinmaa, 2014). However, if subjective need studies are to achieve their full potential to inform needs-based planning of substance use service systems, improve rates of service uptake, and ameliorate the burden of disease associated with SUDs at the population level, key knowledge gaps must be addressed. Below, I outline major shortcomings of extant research and provide the rationale for two studies designed to enhance substance use service system research and planning.

Knowledge gaps and research aims

Taking stock of research on population need for substance use services

Population survey research measuring both objective, expert-determined and subjective, consumer-defined perspectives on need for substance use services are providing useful insights directly relevant for improving SM service system planning and closing the treatment gap. The full scope of this

literature is difficult to appreciate given its interdisciplinary nature (i.e., population surveys of perceived need for substance use services have been published in psychiatry, epidemiology, health services, public health, medicine, drug and alcohol, social work, and criminological journals), as well as its international breadth. Although some authors have systematically described findings from population surveys of objective need for mental health care (Aoun, et al., 2004; Kohn, et al., 2004), or reviewed general approaches to needs assessment in mental health (Joska, & Flisher, 2005; Crook & Oei, 1998), no previous reviews have systematically mapped the literature on population need for alcohol and other drug use services and the extent to which it incorporates expert and consumer perspectives. Moreover, no previous reviews have taken stock of the variety of measurement approaches used to assess subjective service need, nor the potential of subjective need studies to inform service system planning. This is problematic because the implicit aim of research on population need for care is to provide relevant data for improving substance use service planning and resource allocation, and increase uptake into care for people requiring substance use services. These research gaps result in difficulty gauging the full implications of subjective need studies for system planning, and specifying new research directions to further improve understanding of the substance use service 'treatment gap' to reveal strategies for narrowing it.

Thesis objective 1. To address these research gaps, Study 1 in this dissertation consists of a systematic scoping review critically analyzing the literature describing population need for substance use services. Scoping reviews “aim to map rapidly the key concepts underpinning a research area, and the main sources and types of evidence available” (Mays, Roberts, & Popay, 2002, p. 194). They are particularly appropriate when, as here, an area of literature is interdisciplinary, conceptually complex, and has not been systematically reviewed before. My specific aims are to (1) describe the literature on population need for substance use services, and the extent to which it incorporates population survey research measuring objective (expert determined) and subjective (consumer defined) need for care, (2)

critically assess the methodological and measurement approaches used to study subjective need for substance use services, and (3) examine the potential for existing perceived need estimates to inform substance use service system planning. Under these broad research aims, Study 1 addresses the following specific **research questions**:

1. What is the current size of the literature assessing population need for substance use services?
2. Have studies of population need for substance use services increased or decreased over time?
3. In what regions has population need for substance use services been investigated?
4. What proportion of research on population need for substance use services incorporates community-based survey research?
5. What proportion of the population survey research on need for substance use services assesses objective (expert-determined) need?
6. How has objective need for substance use services been conceptualized in population survey research?
7. What proportion of population survey research on need for substance use services assesses subjective (consumer-defined) need?
8. How has subjective need for substance use services been conceptualized in population survey research?
9. For which population groups has subjective need been assessed?
10. What study designs have been used to study subjective need for substance use services?
11. How has the measurement of subjective need for substance use services been approached?
12. To what extent to do studies of perceived need for substance use services generate estimates of required service system capacity?

Understanding subjective need for services amongst street-involved people who use drugs

Relatively little research on population need for substance use services has assessed the needs of socially marginalized, hidden populations (e.g., people who are homeless, street-involved, institutionalized, or sex workers), primarily because telephone and internet-based sampling frames used in general population surveys typically exclude individuals without access to these technologies. Although several epidemiological studies have generated estimates of service needs for hidden populations using disorder prevalence measures (Fazel, Khosla, Doll, & Geddes, 2008), fewer studies have focused on measuring subjective need for substance use and mental health services amongst hidden populations. In particular, very little research has examined subjective need amongst street-involved PWUD. Of the subjective need studies conducted with this population, the majority measure

perceived need for, or self-assessed barriers to either generic substance use 'treatment' (Phillips, et al., 2014; Weschsberg, et al., 2009; Wood, et al., 2005; Myers, Kline, Doherty, Carney, & Wechsberg, 2014; Hadland, Kerr, Li, Montaner, & Wood, 2009; Borders, Booth, Stewart, Cheney, & Curran, 2015; Farabee, Leukefeld, & Hays, 1998) or one specific type of substance use service (e.g., syringe exchange, methadone programs) only (Maher, et al., 2001; Al-Tayyib & Koester, 2011; Ti, et al., 2011; Todd, et al., 2008). Furthermore, just one study (Cruz, et al., 2013) with street-involved PWUD addressed perceived need for services across multiple service categories, and no studies have systematically assessed perceived need for services, service use, unmet service need, and self-assessed barriers across multiple service categories with this population. This is problematic and suggests that extant literature designed to mitigate the treatment gap among marginalized people who use drugs may not be capturing potentially significant variations in levels of perceived need, unmet need, and self-assessed barriers across different service types – further problematizing service planning for these populations.

Thesis objective 2. As outlined earlier in this introductory chapter, in comparison to members of the general and homeless populations, street-involved PWUD experience disproportionate levels of substance use and mental health problems and are at greater risk for related negative health and social outcomes (Falck, et al., 2004; Fischer, et al., 2005; Mackesy-Amiti, et al., 2012; Galea, & Vlahov, 2002; Bruneau, et al., 2012; Roy É, et al., 2004; DeBeck, et al., 2011). At least some of this disproportionate burden of disease may be attributable to unmet need for care for SUDs.

Street-involved PWUD tend to experience high rates of socioeconomic marginalization, unemployment, and problem severity as compared with non-street involved people (Richardson, et al., 2010; Richardson, et al., 2015). However, a number of studies have documented heterogeneity in this population including important gradients in housing status (Kerr, et al., 2005; DeBeck, et al., 2012; DeBeck, et al., 2011; Wechsberg, et al., 2003) and severity of substance use problems (Lundgren, et al., 2005; Surratt, et al., 2005; Fischer, et al., 2005; Lemstra, et al., 2011). These findings suggest that the

extent of socioeconomic marginalization (e.g., housing instability) and problem severity (e.g., heavy substance dependence) may be associated with higher rates of unmet service need even within street-involved populations. However, these predictions have not been tested empirically. Thus, thesis objective 2 aims to examine perceived need, perceived unmet need, and self-assessed barriers to services for substance use and mental health problems amongst a sample of 320 street-involved PWUD. My specific **research questions** were:

1. What is the level of perceived unmet need for substance use and mental health services amongst socially marginalized PWUD?
2. Do correlates of perceived unmet need particularly extent of socioeconomic marginalization and problem severity predict unmet service needs amongst street-involved PWUD?
3. Do street-involved PWUD endorse motivational barriers to care for substance use and other mental health disorders, or are structural barriers more commonly endorsed amongst this group?

The following chapters present two manuscripts designed to address my first and second research objectives, respectively. The concluding chapter of this dissertation synthesizes the findings of these two studies, presents recommendations for future research in this area, and discusses policy implications for substance use service system planners attempting to improve access to care, and reduce the health, social, and economic costs of SUDs in general and/or hidden populations.

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Chapter 2: Estimating population need for substance use services: A critical analysis of 35 years of research on expert and consumer perspectives

Abstract

Background. Effective substance use services often fail to reach many alcohol and other drug misusers in the community. Recognition of this treatment gap has stimulated research estimating population need for substance use services. This scoping review was designed to (a) characterize the extent to which research incorporates estimates of service need derived from expert and consumer perspectives, (b) assess how consumer-based need has been studied, and (c) consider the potential of this research to inform service system planning.

Methods. Systematic searches of 7 databases (Medline®, EMBASE®, EBSCO CINAHL Plus®, Scopus®, Web of Science® Core Collection, and Evidence-based Medicine Reviews®) for articles published between 1980 and May 2015 identified 1930 relevant articles, of which 1594 reported empirical results from population surveys. Survey research was coded for adopting expert and/or consumer perspectives on need for services and other study features. A subset of 217 population survey studies that used subjective, consumer-derived measures of service need received in-depth coding.

Results. Almost all population survey research (96% of those studies) directly estimated need for services using an objective, expert-defined approach (e.g., prevalence and patterns of substance use, prevalence of diagnosable disorders, service utilization). Of the small number (14%) of survey research studies that used a subjective, consumer-defined approach, most measured perceived need for services (77%), with fewer examining self-assessed barriers to service use (42%) or informal help seeking from family and friends (10%). Very little research was longitudinal or tested hypotheses, and single-item measures were commonly used to assess consumer perspectives on need for services. Only one published study incorporated a subjective need estimate to calculate required service system capacity.

Conclusions. Rhetorical calls for including consumer perspectives into service planning are belied by the empirical literature, which is dominated by objective, expert-defined measures of population need for substance use services. The published literature reveals virtually no accounts of how estimating population need for services relates to service system planning. A limited subset of this literature addressing consumer-defined need for substance use services is conceptually underdeveloped, and studies exhibit methodological and measurement weaknesses. Further research is needed to harness the promise of incorporating consumer perspectives into service system planning.

Introduction

Over the past four decades, significant progress has been made in the treatment of substance use disorders (Wood, Samet, & Volkow, 2013). A large international literature shows that 'treatment works,' with evidence that a variety of treatment interventions and supports produce significant reductions in substance misuse and improve the health and social functioning of people seeking help for problems with alcohol and other drugs (Babor, 2015, Dutra et al., 2008; Kimber et al., 2010; Ries, Miller, Saitz, Fiellin, & American Society of Addiction Medicine, 2014; Ritter & Cameron, 2006; Strang et al., 2012). Despite this progress, substance use disorders continue to affect almost 150 million people worldwide (Whiteford, Ferrari, Degenhardt, Feigin, & Vos, 2015) and many never receive care for these conditions. Misuse of alcohol and other drugs is a growing cause of noncommunicable disease burden, accounting for 2.9 million deaths and over 120 million disability-adjusted life-years (DALYs) in 2010 alone (Degenhardt & Hall, 2012; Lim et al., 2012). Alleviating suffering by closing this treatment gap has been declared a global mental health priority (Lancet Global Mental Health Group, 2007).

In the United States and elsewhere, concerted efforts to scale up population access to substance use services and supports began in the 1980s (Institute of Medicine Committee for the Study of Treatment and Rehabilitation Services for Alcoholism and Alcohol Abuse, & National Institute on Alcohol Abuse and Alcoholism, 1990; Rush, 2010; Mechanic, 2003). These efforts were accompanied by studies attempting to estimate population need for care in relation to existing service coverage. This reflected a shift away from research characterizing the demographic and clinical correlates of treatment-seekers, toward community-based, public health studies of need for services in both general and special populations, regardless of whether general health care or specialty addiction treatment was actually sought or received (Horwitz & Grob, 2011).

Conceptualizing population need for substance use services

Initial approaches used indirect estimation techniques designed to quantify need for services in relation to the prevalence of substance use and misuse in the general population, using a variety of statistical

models applied to administrative datasets (e.g., retail alcohol sales, mortality data, HIV testing databases) (Crook & Oei, 1998; Dewit & Rush, 1996; Fiorentine, 1994; Ford, 1985). However, administrative datasets often have limited capacity to inform service system planning because they typically do not differentiate between subpopulations that might benefit from different types of services in relation to problem severity, e.g., substance misusers versus those meeting diagnostic criteria for substance use disorders; or people who do and do not exhibit comorbid substance use and mental disorders. These limitations hinder efforts to estimate how many people in the general population could benefit from accessing the variety of treatment interventions and supports for substance misuse typically offered by general health care and speciality service systems (e.g., brief interventions, outpatient care, speciality residential treatment) (Dewit & Rush, 1996).

More recently, research turned to direct estimation methods using community-based population surveys. These approaches attempt to quantify population need for services in relation to prevalence of substance use disorders, as assessed by structured diagnostic instruments (e.g., the Composite International Diagnostic Interview [CIDI]) (Horwitz & Grob, 2011; Kohn, Saxena, Levav, & Saraceno, 2004). The Epidemiological Catchment Area Program (ECA; 1980-1985) (Regier et al., 1993) and the first iteration of the National Co-Morbidity Study (NCS; 1990-1992) (Kessler et al., 1994) were two early examples of this approach. These seminal studies clearly documented that most people meeting diagnostic criteria for substance use disorders do not access health services. Past year general health care and specialty treatment rates in the ECA were 23.6% for respondents meeting diagnostic criteria for any substance use disorder (Regier et al., 1993), and varied between 11.6% (alcohol abuse) to 46.8% (drug dependence) in the NCS (Narrow, Regier, Rae, Manderscheid, & Locke, 1993). Other countries have since implemented large population-based mental health surveys with similar results (Bijl et al., 2003; Kohn et al., 2004).

Expert versus consumer perspectives on population need for services

These consistent findings of large treatment gaps for substance use and other mental health problems led to questions about the validity of diagnostic systems used in population-based studies of service needs.

Some speculated that disorder prevalence estimates were inflated, and not a true reflection of actual need for care in the population (Mechanic, 2003; Horowitz & Grob, 2012). Several changes were subsequently made to the fourth edition of the Diagnostic and Statistical Manual (DSM-IV) and the CIDI in order to provide information to complement diagnoses, including clinical significance, impairment, and disability (American Psychiatric Association, 2000; Kessler, 2000; Regier, 2003). Although these changes yielded more conservative prevalence estimates (Regier, 2003), they continued to prioritize an objective, expert-derived perspective on population need for services. This priority has been called into question, however, in light of growing evidence that diagnostically-assessed need for care is only modestly predictive of actual service use (Demyttenaere et al., 2004; Kessler et al., 2005; Mechanic, 2003; Minoletti et al., 2012; Regier, 2003). For example, Demyttenaere and colleagues (2004) reported that across seven high-income countries, 36 to 50 percent of respondents meeting diagnostic criteria for severe substance use and mental disorders reported no past year service use; and that most individuals receiving care were 'subthreshold' cases that exhibited low-severity problems, or failed to meet objective, expert-derived diagnostic criteria (Mechanic, 2003; Minoletti et al., 2012).

From a broader health system perspective, the deinstitutionalization of mental health and substance use services that occurred in the latter part of the 20th century coincided with the development of service delivery models explicitly conceptualizing patients as active participants in health care, with the ability to make treatment decisions based on their own sense of well-being (Tomes, 2006). These models imply that population need for care for substance misuse is a socially negotiated process that is at least partially determined by consumer perceptions of need for care (Druss, 2007; Meadows, Harvey, Fossey, & Burgess, 2000a; Slade, 1994). The importance of subjective, consumer-defined need for services echoes Andersen's (1995) influential model of healthcare utilization, wherein predisposing and enabling factors affect individual perceptions of health care needs, and these perceptions are theorized to be a proximal determinant of service use. From this perspective, assessing consumers' subjective views on service need is at least as important as determining disorder prevalence rates for researchers attempting to quantify population need for services with

an eye toward service system planning (Druss, 2007; G. Meadows et al., 2000). Two related concepts emphasizing a subjective, consumer-derived perspective: self-assessed barriers to care (Nelson & Park, 2006), and help seeking from friends or family members (potentially in lieu of formal service use) (Reavley, Yap, Wright, & Jorm, 2011), have also been examined in this regard.

Emerging research incorporating consumer perspectives on service need demonstrates that only about 10 - 30 percent of individuals who meet objective diagnostic criteria for substance use disorders actually perceive a need for care (Rush, Urbanoski, Bassini, Castel, & Wild, 2010; Meadows & Burgess, 2009; Mojtabai & Crum, 2013; Mojtabai, Olfson, & Mechanic, 2002), and that perceiving a need for care is strongly associated with service use (Green-Hennessy, 2002). Individuals who do perceive a need for services, but do not have this care need met, report high levels of disability and distress (Urbanoski, Cairney, Bassani, & Rush, 2008), which tend to improve once care needs are met (Meadows & Burgess, 2009). However, 5 - 21 percent of individuals who access services, nevertheless still report service needs have not been met (Rush et al., 2010; Chen et al., 2013; Meadows & Burgess, 2009; Melchior, Prokofyeva, Younès, Surkan, & Martins, 2014; Urbanoski et al., 2008). Research on subjective, consumer-defined need for services also demonstrates that motivational or attitudinal barriers—such as a desire to self-manage one's own symptoms—appear to be more common than cost or other structural barriers, as reasons for having unmet care needs (Nelson & Park, 2006; Oleski, Mota, Cox, & Sareen, 2010; Sareen et al., 2007). Collectively, the above findings suggest that objective, expert-derived measures of population need (i.e. prevalence of alcohol and other drug misuse, prevalence of substance use disorders, and/or service utilization rates) are necessary, but may be insufficient for generating robust estimates of population need for services.

Research aims

Direct estimation using surveys has become a recommended approach for making inferences about population need for substance use services (Minoletti et al., 2012), and several studies have used data on objective, expert-derived population need to estimate required service system capacity (Aoun, Pennebaker, &

Wood, 2004; Belenko & Peugh, 2005; McAuliffe & Dunn, 2004). However, many have called for complementing diagnostically-oriented approaches to direct estimation with subjective, consumer-derived measures (Aoun et al., 2004; Minoletti et al., 2012), since they have the potential to provide a more complete assessment of population need for services (Ritter, 2013; Rush et al., 2014; Wild, Wolfe, Wang, & Ohinmaa, 2014).

Unfortunately, to our knowledge, no previous reviews have systematically mapped the literature on approaches to assessing population need for substance use services and the extent to which it incorporates expert and consumer perspectives. Moreover, no previous reviews have taken stock of the variety of measurement approaches used in this literature, nor the extent to which estimates of perceived need for services actually inform service system planning. To address this gap, we conducted a systematic scoping review to critically analyze the literature describing population need for substance use services. Scoping reviews "aim to map rapidly the key concepts underpinning a research area, and the main sources and types of evidence available" (Mays, Roberts, & Popay, 2002, p. 194). They are particularly appropriate when, as here, an area of literature is interdisciplinary, conceptually complex, and has not been systematically reviewed before. Our specific aims are to (1) describe the literature on population need for substance use services, and the extent to which it incorporates population survey research measuring objective (expert determined) and subjective (consumer defined) need for care, (2) critically assess the methodological and measurement approaches used to study subjective need for substance use services, and (3) examine the potential for existing perceived need estimates to inform substance use service system planning.

Methods

Our study protocol was adapted from Arksey and O'Malley's (2005) scoping review framework. Although our review was not intended to assess study quality or synthesize research evidence, the PRISMA reporting guidelines for systematic reviews (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) informed the reporting of our results.

Search strategy

LS (a professional health sciences research librarian) led the development of our systematic search strategy and executed the final search. We conducted multiple test searches using an *a priori* list of keywords and subject headings to develop and refine multiple database-specific controlled vocabularies (Appendix 1) designed to identify relevant studies using a broadly inclusive approach based on two central concepts: 'substance use services' and 'population need assessment.' We searched seven databases including Medline®, EMBASE®, PsycInfo, EBSCO CINAHL Plus®, Scopus®, Web of Science® Core Collection, and Evidence-based Medicine Reviews® to maximize the breadth of our results. The scope was limited to English language, peer-reviewed journal articles and book chapters [not editorials/commentaries, conference abstracts, letters, or dissertations] published between 1980 and May 28, 2015 and available via the University of Alberta holdings. Our search identified 23,005 records. A total of 8736 duplicates were removed, leaving a sample of 14,269 unique records.

Screening

Titles and abstracts of all records were screened for relevance by EH, GK, and BT. Articles were included if they: (1) described prevalence and patterns of substance use, problematic substance use, substance use disorders, substance use service utilization, or help-seeking; and (2) recruited samples of substance users from community settings; and/or (3) outlined one or more methods for assessing population need for services or estimating required capacity of substance use services to meet population need for care; and/or (4) reviewed literature on methodological or conceptual issues in population need assessment to inform substance use services. Articles were excluded if they: (1) described need for substance use services exclusively amongst treatment-seeking or clinical samples; (2) described need for services not intended to mitigate substance use problems directly (e.g., HIV prevention, Hepatitis C treatment, dental care); (3) described service needs among populations experiencing mental disorders only, i.e., excluded substance use disorders; (4) measured intervention effectiveness or cost-effectiveness; or 5) narratively summarized empirical findings of previous

population need studies.

To ensure consistency in the screening process, raters independently screened a common set of 50 records, and in preliminary work, assessed and monitored inter-rater agreement on triaging decisions using Light's Kappa coefficient (Davies & Fleiss, 1982; Light, 1971).). Instances of disagreement were discussed and the inclusion and exclusion criteria were refined and clarified, as necessary. An iterative process involving 10 batches of 50 records was executed, followed by research team discussion, until acceptable inter-rater agreement on article screening was reached (Light's Kappa > 0.8). During this process, in cases of disagreement, three or more members of the research team discussed any questions regarding the relevance of a particular record collectively, until a consensus was reached and an acceptable kappa estimate was demonstrated. Screening then proceeded independently among the raters, although eight additional sessions were conducted periodically to verify that acceptable agreement regarding screening decisions (Light's kappa = 0.8 or greater) was maintained throughout the screening stage. The title and abstract screening stage identified 2138 potentially relevant records. The full text of each record was then reviewed by EH, and relevant data extracted based on a standard coding framework. During this process, an additional 208 articles were determined to be ineligible or met exclusion criteria. The remaining 1930 articles are included within the scope of this review. Appendix 2 provides our systematic search strategy flow diagram using the PRISMA guidelines.

Data extraction

A coding framework (see Appendix 3) for included articles was iteratively defined and developed deductively (using knowledge of the literature) and inductively (using preliminary analysis of the included articles). All articles were coded for: single or cross-national study; country; country type (high, middle or low income); global region; and whether or not they reported empirical data. All empirical articles (n = 1887) were coded according to the type(s) of data used to derive estimates of service need (administrative datasets, biological samples, qualitative data, or quantitative survey data). All empirical studies using quantitative survey data (n = 1594) were classified according to whether they used one or more objective, expert-determined

population need measures (i.e., substance use prevalence, disorder prevalence, service utilization rates) and/or one or more subjective, consumer-derived measures (i.e., perceived need for services, self-assessed barriers to service use, and/or self-reported help-seeking from family or friends).

In-depth coding was conducted on all studies containing one or more measures of subjective, consumer-defined need for services (n = 217; Appendix 4 contains a complete list of articles meeting the review inclusion criteria). These articles were coded for: study design (cross-sectional or longitudinal); target population (general [all members of adult population in a given jurisdiction], special [eligibility criteria include membership in a specific subpopulation, e.g., college students] or user-only [study eligibility criteria include reporting substance use]); participant characteristics (sample size, age, sex, types of substances used); measurement (use of single, multi-item and standardized measures); and analytical approach taken (descriptive vs. hypothesis-driven analyses reported). We also coded whether or not each study estimated required service system capacity using one or more measures of perceived need for services. All subjective, consumer-defined need articles were double coded by GK and BT. Disagreements were discussed with EH and corrected as appropriate.

Results

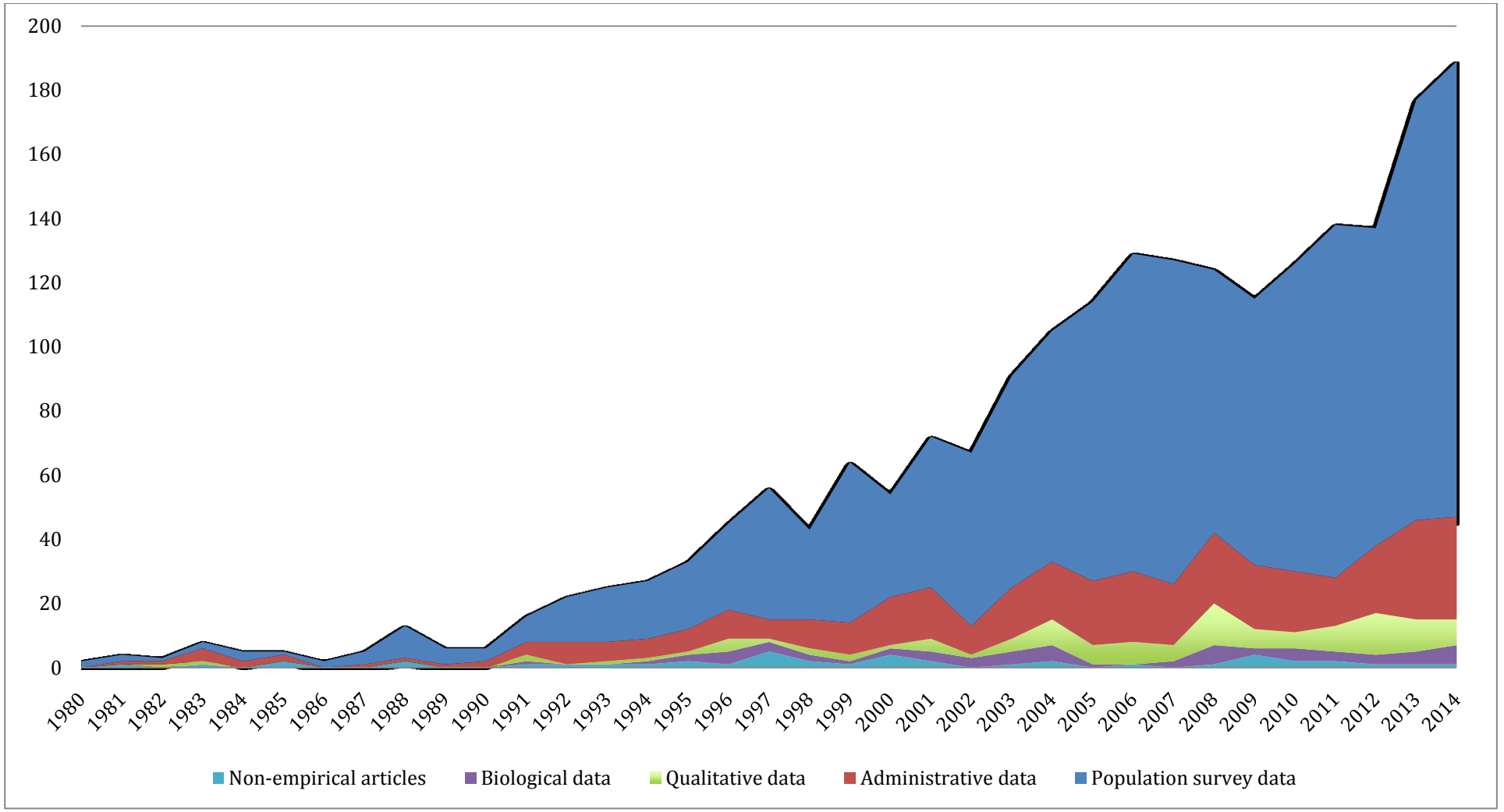
Approaches to estimating population need for substance use services

Our scoping review identified 1930 articles. Figure 2-1 describes these articles by data source and publication year. Overall, 43 articles were non-empirical, and amongst the remaining 1887 empirical articles, 83% (n = 1594) estimated population need using quantitative survey data, 20% (n = 380) used administrative datasets, 6% (n = 116) used qualitative data, and 3% (n = 62) used biological samples (e.g., urinalysis, wastewater analyses). These percentages do not sum to one hundred, as a proportion of these articles (13%; n = 251) used more than one type of data source.

Almost all population survey studies (95%; n = 1512) reported data collected from within one country only. Amongst these studies, 88% (n = 1335) were conducted in high-income countries, with over half (56%; n =

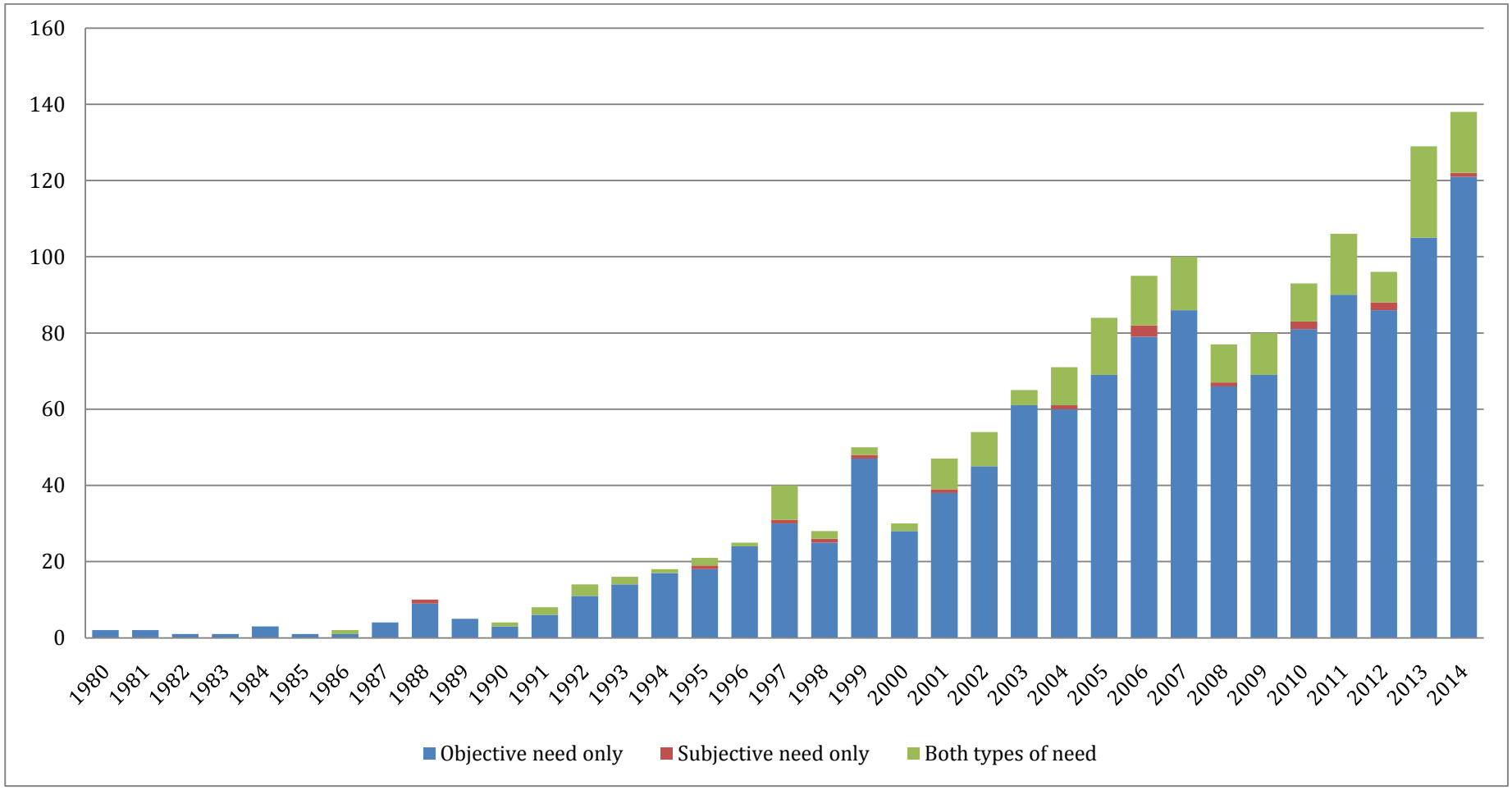
853) in the United States alone. The vast majority (84%; n = 1334) of population survey studies were published between 2000 and 2015, with 38% (n = 611) published since the start of 2010. Figure 2-2 outlines the extent to which population survey studies (n = 1594) used objective (expert defined) and/or subjective (consumer defined) approaches to estimate population need for substance use services, over time. In total, 96% (n = 1534) of survey research articles reported data derived from one or more objective need measures, and 84% (n = 1333) reported objective estimates exclusively. In contrast, only 14% (n = 217) of all survey research articles reported data derived from one or more subjective need measures. The majority (93%; n = 201) of the articles reporting subjective need estimates also included objective need estimates, and only 16 articles (7%) reported subjective estimates exclusively. Note that a small number (3%; n = 44) of population survey studies met study inclusion criteria, but did not use either an objective or subjective measure of population need for services. Examples of these articles include studies measuring spatial access to substance use services (e.g., Cooper et al., 2011), studies evaluating the reach of various sampling techniques (e.g., Wang et al., 2005), and 'user-only' studies—studies restricting the sample to those using alcohol and other drugs, i.e., research that described demographic (or other characteristics) of substance users, but not objective or subjective service need (e.g., van de Mheen, van der Poel, Lempens, & Maalsté, 2007).

Figure 2-1. Frequency of studies addressing population need for substance use services by data type, and year (n = 1930)



[1]39 studies published between January 1 and May 28 2015 were excluded from this figure due to incomplete data for 2015.

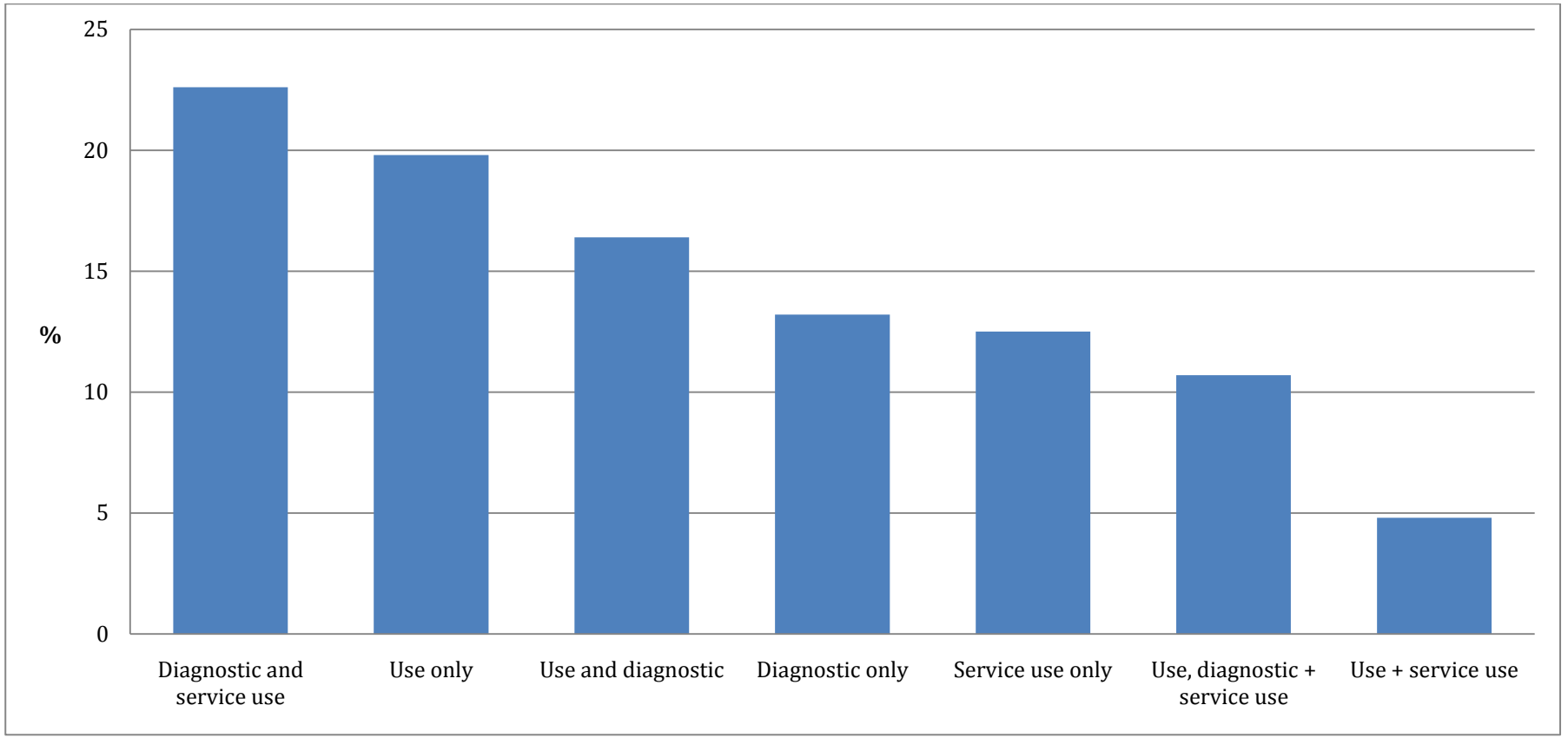
Figure 2-2. Frequency of survey research studies containing one or more measures of objective need, subjective need, or both objective and subjective need, by publication year (n = 1594)



[1] Objective need defined as: reporting one or more of: prevalence of substance use, prevalence of disorders (using some expert diagnostic criteria), and/or substance use service utilization rates. Note that 'user-only' studies (i.e., studies where eligibility criteria included substance use) were only coded as reporting a substance use prevalence estimate when survey data were combined with administrative data to estimate population prevalence of use.

[2]Subjective need defined as: reporting one or more of: perceived need for substance use services, self-assessed barriers to accessing substance use services, and/or informal help-seeking from family or friends.
[3] 36 studies published between January 1 and May 28 2015 were excluded from this figure due to incomplete data for 2015.

Figure 2-3. Percent of expert-defined service need studies using specific combinations of objective need measures (n = 1534)



[1] Use refers to substance use prevalence, defined as an estimate of the population prevalence of one or more types of substance use. Note that 'user-only' studies (i.e., studies where eligibility criteria included substance use) were only coded as reporting a substance use prevalence estimate when survey data were combined with administrative data to estimate population prevalence of use.

[2] Diagnostic refers to diagnostic prevalence defined as meeting criteria for one or more substance use disorders or problematic patterns of substance use.
[3] Service use is defined as reporting use of one or more substance use services (general health, social, or specialty substance use and mental health services).

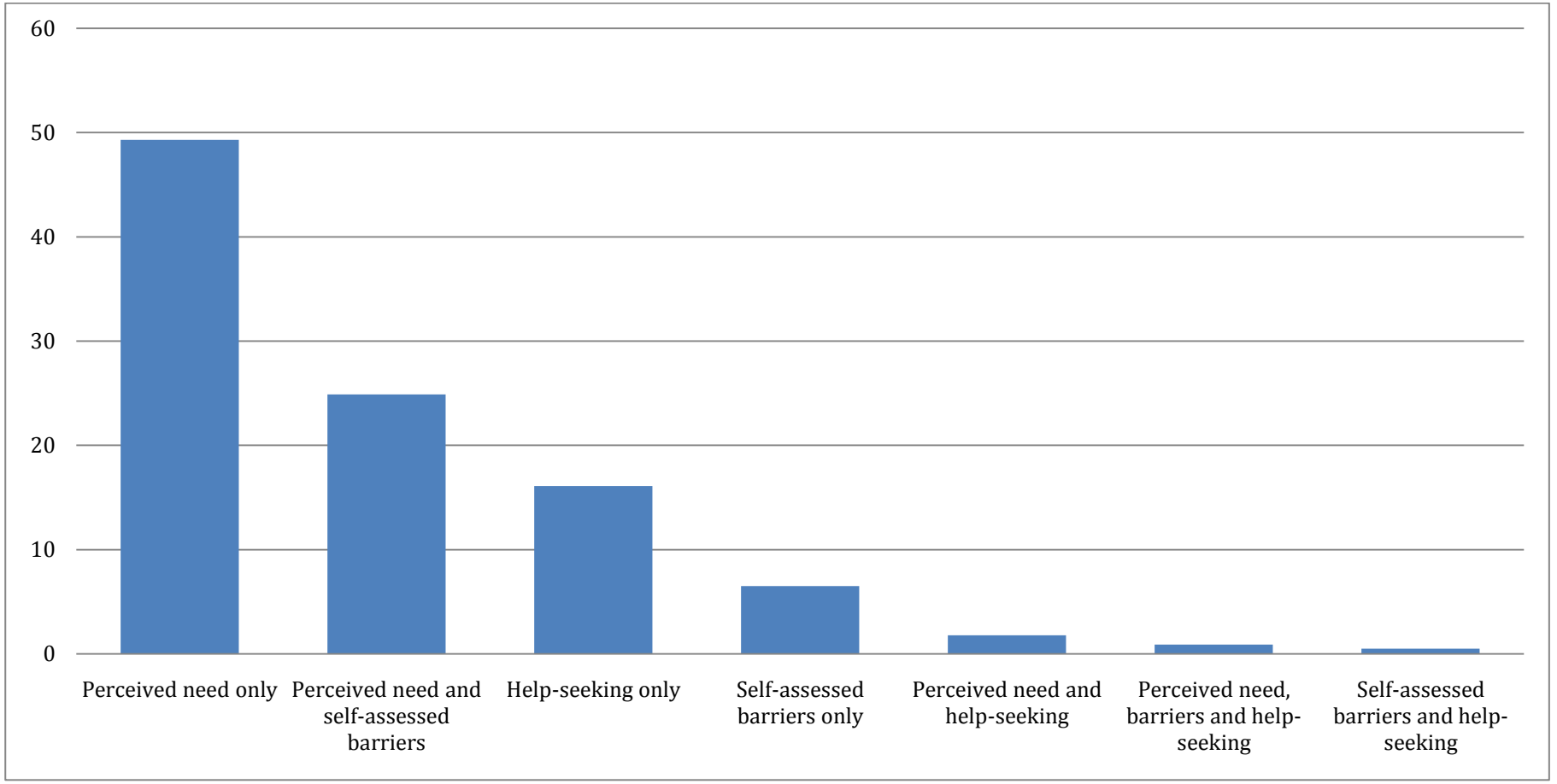
Population need for services: Objective measurement approaches

Amongst objective need studies, 63% (n = 965) reported diagnostic prevalence, 52% (n = 794) reported substance use prevalence, and 51% (n = 776) reported rates of service use. Figure 2-3 illustrates how objective need has been measured and conceptualized in the literature on population need for substance use services. Almost one quarter of objective need studies (23%; n = 346) report both diagnostic prevalence and service use estimates. However, studies reporting only estimates of substance use prevalence (20%; n = 304) are also common. Only 10.7% (n = 165) of studies report data derived from all three objective need measures, making this one of the least common approaches for objectively assessing population need.

3.2 Methodological approaches for studying subjective need

In-depth coding of subjective need studies indicated that, with regard to target populations, 36% (n = 77) of subjective need studies recruited 'user-only' samples, where participants were required to report substance use to be eligible for the study. Most of these studies recruited unspecified drug users (31%; n = 24), injection drug users (25%; n = 19), or stimulant users (22%; n = 17). Some of these studies also had additional eligibility criteria, such as being HIV positive, street-involved, or pregnant. Studies conducted with representative samples of general adult populations also comprised a significant proportion (35%; n = 76) of research on subjective need for substance use services. Of these, 83% (n = 63) reported findings from the United States, 8% (n = 6) from Canada, 3% (n = 2) from Australia, with the remaining proportion comprised of individual studies from New Zealand, the United Kingdom, Mexico, China, and South Korea. Additionally, 30% (n = 64) of subjective need studies were conducted amongst members of special populations. The most common special populations studied were adults and youth involved in criminal justice systems (34%; n = 24) and people experiencing homelessness (25%; n = 16). However, other special populations represented included military members, students, ethnic and sexual minorities, people with low incomes, professionals, sex workers, and sexual assault survivors.

Figure 2-4. Percent of consumer-defined service need studies using specific combinations of subjective need measures (n = 217)



[1]Perceived need defined as an individual's judgment about whether they require substance use services.
[2]Self-assessed barriers defined as an individual's judgment regarding factors that impede substance use service utilization.
[3]Help-seeking defined as self-reporting seeking help from family or friends for substance use problems.

Table 2-1. Examples of single and multiple item measures used to assess subjective need in research on population need for substance use services (n = 217)	
Single item measures	
Perceived need[1]	*"Do you feel you could use treatment for drug or alcohol use?"* (Baldwin, et al., 1995) *"During the past 12 months, was there ever a time when you felt that you needed help for your emotions, mental health, or use of alcohol or drugs, but you didn't receive it?"* (Urbanoski, et al., 2008) Participants were read the following statement: *"I now need to get into a drug abuse treatment program."* They were asked to answer along on a 5 point scale ranging from "strongly disagree" to "strongly agree." (Falck, et al., 2007)
Self-assessed barriers to service use[2]	*''Have you ever thought you should seek help for drinking, but you did not go?''* Those answering yes were queried about the reasons for not seeking treatment. Answers were grouped into financial, structural, attitudinal and other categories. (Kaufmann, et al., 2013) For all persons who reported having difficulty accessing needles, the following question was then asked: *''If yes or sometimes, why do you find it hard to get new [unused] rigs?*'' The interviewer did not read out a list of possible explanations, but had a list of nine possible responses as well as space to note answers that did not fit with one of the nine categories. (Wood, et al., 2002)
Help-seeking from family and/or friends[3]	*"On the last occasion, how did you try to change your drug use?"* (response categories: by myself; with family/friends; home detoxification; residential detoxification; methadone; doctor; counsellor; Alcoholics Anonymous) (Carruthers, et al., 1998) Participants were asked whether they had used a range of smoking-cessation support and aids in the last year (family and friends were one source queried) (Edwards, et al., 2007)
Multiple item measures	
Perceived need	Participants were asked three items with five-point response scales ranging from strongly disagree to strongly agree: (I) *"In terms of the things I need right now, getting into drug abuse treatment is at the top of the list"; (2) "I now need to get into drug abuse treatment for drug addiction"; and (3) "Because of my drug use, I now need drug abuse treatment."* The sum of the scores on these items comprised a composite measure of the perceived need for treatment. Scores could range from 3 – 15. (Brook, et al., 2006) "*Did you think you needed help for alcohol or drug problems*?" Those with a perceived need were asked, "*Were there any times during the past 12 months when you got less treatment for emotional, mental health, alcohol, or drug problems than you needed, or had difficulties or delays in getting care*?" (Falck, et al., 2002)
Self-assessed barriers to service use	Administered checklist of 36 commonly cited reasons for not seeking treatment for alcohol & drug dependence. Items pertain to areas like feelings, coping with stress (family, financial and personal), perceived useful effects of drugs, cost of treatment, perceived effectiveness, treatment related fears and social reasons. The answers were recorded as Yes / No. (Arun, et al., 2004) "Veterans may face obstacles getting or using mental health services for a number of reasons. Please rate how much you agree or disagree with each statement as it applies to you." 17 statements related to treatment effectiveness (example, "I don't think treatment

	will help me"), to stigma ("I would be seen as weak by others"), and to external barriers ("It's hard getting time off work for treatment") listed. Responses ranked on a 4-point scale: 1, strongly disagree; 2, somewhat disagree; 3, somewhat agree; and 4, strongly agree. (Elbogen, et al., 2013)
Help-seeking from family and/or friends	Participants were asked to rank the perceived helpfulness of 34 interventions and whether they were used in the previous two years. "Close friend" and "close family" were two interventions listed. (Reavley, et al., 2011) Participants were asked whether they had sought help from family and/or friends to reduce/cease methamphetamine use in the past 30 days. A second measure asked about help from family and/or friends in the past 12 months. (Quinn, et al., 2013)

[1]Perceived need defined as an individuals' judgments about whether they require substance use services.
[2]Self-assessed barriers defined as an individual's judgment regarding factors that impede substance use service utilization.
[3]Help-seeking defined as self-reporting seeking help from family or friends for substance use problems.

Table 2-2. Standardized measures used to assess subjective need in research on population need for substance use services[1] (n = 217)		
Variable	*Instrument*	*Cited in*
Perceived need[2]	*Texas Christian University's Self-Rating Psychosocial Functioning and Motivational Scales* (Knight, et al., 1994)	Belenko, et al., 2003
	Stages of Change Readiness and Treatment Eagerness Scale- Version 8 Combined (Miller, & Scott, 1996)	Brubaker, et al., 2013
	Revised Risk Behaviour Assessment (Wechsberg, 1998)	Myers, et al., 2014
	Perceived Need for Care Questionnaire (Meadows, et al., 2000)	Meadows, & Burgess, 2009; Sareen J, et al., 2007; Sareen, et al., 2010
	National Technical Centre (NTC) Telephone Substance Dependence Needs Assessment Questionnaire (McAuliffe et al., 1995)	O'Toole, et al., 2004
	Self-help and Treatment Services Utilization Survey (Fontana, et al., 2006)	Whealin, et al., 2014
	Camberwell Assessment of Need - Forensic Short Version (Thomas, 2003)	Baksheev, et al., 2010; Chitsabesan, et al., 2012
	University of Miami Health Services Research Instrument (McCoy, et al., 2001)	McCoy, et al., 2001
Self-assessed barriers to service use	*Affordability barriers scale* (Meyers, et al., 2002)	Myers, 2013; Myers, et al., 2011; Myers, et al., 2010
	Allen Barriers to Treatment Instrument (Allen, 1994)	Wu, et al., 2012
	Barriers Questionnaire (Green, 2011)	Venner, et al., 2012
	Barriers to Treatment Instrument (Miller, et al., 2008)	Brubaker, et al., 2013
	Barriers to Treatment Inventory (Rapp, et al., 2006)	Kelly, et al., 2014
	University of Miami Health Services Research Instrument (McCoy, et al., 2001)	McCoy, et al., 2001
Help-seeking from family and/or friends	*Mental and physical health questionnaire* (Lennings, et al., 2006)	Lennings, et al., 2006
	Michigan alcoholism screening test (Selzer, 1971)	Ullman, & Najdowski, 2010

[1] In some cases, one or more measures, but not all measures included in the standardized instrument where used to measure subjective need.
[2] One article measuring perceived need did not specify the name of the standardized instrument used.

Sample sizes ranged between 18 and 336 003 across subjective need studies. In terms of sample demographics, most (86%; n = 185) subjective need studies included both male and female participants. The mean age of participants ranged from 13 to 75 (amongst the 108 studies where this information was reported). Finally, with regards to study design, the majority of subjective need studies adopted a cross-sectional (86%; n = 187) rather than longitudinal design, and produced descriptive analyses (79%; n = 172), rather than testing specific hypotheses.

Approaches to measuring subjective need

Most studies (77%; n = 167) reported perceived need estimates, with far fewer measuring self-assessed barriers to service use (42%; n = 92), or help seeking from family or friends (10%; n = 21). Overall, 72% (n = 156) of these studies included only one subjective need measure. Figure 2-4 illustrates the variety of ways subjective need was assessed. Almost half (49%; 107) of all studies assessing subjective need for substance use services estimated perceived need only, and one quarter (25%; n = 54) reported data on perceived need and self-assessed barriers. We identified only two studies (1%) examining all three subjective need measures together.

Subjective need for substance use services has been assessed using a variety of single, multiple item, and standardized measures. The majority of both studies measuring perceived need (68%; n = 113), and those measuring help seeking (71%; n = 15) assess these constructs using single item survey measures. Just over half (51%; n = 92) of studies measuring self-assessed barriers to service use adopted multiple-item survey measures (measurement details were not specified in 19% (n = 14) of these studies). Table 2-1 illustrates the diversity of single and multiple item subjective need measures we identified. Of note, subjective need measures tended to define substance use services using a variety of

different terms and phrases. For example, amongst studies assessing perceived need for services, 84% (n = 140) of measures referred to generic substance use treatment only, whereas the remaining 26% (n = 27) of studies asked about need for one or more specific service types (such as counselling, pharmacotherapy, mutual help groups, needle exchange services, etc.). Very few of the survey research articles identified in our review implemented standardized instruments to measure subjective service need. For example, perceived need was measured using a standardized instrument in only 7% (n = 12) of articles measuring this construct. Use of standardized instruments was slightly more common for articles measuring self-assessed barriers to service use (9%; n = 8), and help seeking from family and friends (9%; n = 2). Table 2-2 provides a complete list of all standardized measures of subjective need uncovered in our review.

To what extent do current estimates of perceived need inform substance use service system planning?

As outlined at the start of this review, measuring subjective, consumer-defined need for services is an important endeavor for improving understanding of the substance use disorder treatment gap, and estimates of perceived need, in particular, have the potential to enhance substance use service system planning. We examined the extent to which subjective need studies have incorporated data on perceived need into estimates of required system capacity to meet population need for substance use services. We identified only one study (n = 1; 0.1%) where perceived need estimates were used to calculate required service system capacity. The study was published in 1991 by (McAuliffe, Breer, Ahmadifar, & Spino, 1991) and used telephone survey data to estimate the number of residential substance use treatment spaces needed to meet existing levels of perceived need in Rhode Island.

Given the lack of required system capacity estimates in the perceived need literature, we also considered the extent to which data reported in these articles could *hypothetically* be used to inform system planning. To do this, we calculated how many articles contained, at minimum, an estimate of substance use disorder prevalence, service utilization, and perceived need for a given sample or population. We selected these variables because they are the most basic measures required to incorporate perceived need into estimates of required service system capacity (Rush et al., 2014). In total, 63% (n = 106) of all perceived need articles contained all three measures, and could potentially be used to inform substance use service planning. Half of these articles (n = 54) were derived from general population surveys.

Discussion

This scoping review provided a broad overview of the state of the literature on assessing population need for substance use services. We were particularly interested in the extent to which objective, expert-defined and subjective, consumer-derived perspectives were represented in survey research measuring population need. Because of recent interest in consumer perspectives in efforts to improve direct estimation methods to quantify population need for services (Meadows et al., 2000), we also critically assessed the methodological and measurement approaches used to study subjective need for substance use services and their potential for informing substance use service system planning. Survey research on population need for substance use services is growing exponentially, with over 600 studies conducted since 2010 alone. However, the imperative to study subjective need–implied both by recognition of the limitations of using diagnostic prevalence to predict service use, and Andersen's (1995) influential model of health services utilization—is belied by the overwhelming emphasis on

objective, expert-defined measures in the extant literature. Our review identified relatively few survey research studies assessing population need for substance use services, which incorporated any measure of subjective, consumer-defined need. This finding is puzzling, given recognition of the importance of individual perceptions on health in other areas of epidemiology (i.e., the concept of 'lay epidemiology'; [Davison, Smith, & Frankel; 1991; Lawlor, Frankel, Shaw, Ebrahim, & Davey Smith, 2003]) and social sciences research (Mark & Paul, 2005).

There are several plausible explanations for the dearth of consumer-derived measures in survey research on population need for substance use services. Overemphasis on expert conceptions undoubtedly reflects broader challenges of incorporating consumer perspectives into mental health decision-making. Traditionally, psychiatry and other mental health disciplines have granted consumers little-to-no control over mental health services and individual treatment plans (Kent & Read, 1998). Moreover, those disagreeing with a diagnosis or prescribed treatment were often labeled as in denial, lacking insight, or irrational (Finn, Bailey, Schultz, & Faber, 1990). While a strengthening consumer movement is amplifying patient voices and informing mental health care (Kent & Read, 1998; Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Tomes, 2006), results of this review suggest that consumer perspectives have yet to exert significant influence. That influence is over clinical, epidemiological, social science, or health services researchers interested in the substance use treatment gap generally, and in estimating population need for services more specifically.

Another possibility relates to our finding that over half of all research on population need for substance use services has been conducted in the United States, where consumer perspectives on need for services may be particularly contentious. In contrast to other jurisdictions, the United States is home

to an abundance of private, for-profit managed behavioural health care organizations and until fairly recently, has been embroiled in debates over state legislation mandating parity in insurance coverage for medical/surgical and mental health and substance use disorders (Mechanic, 2003; Regier, 2003). Consequently, definitions of 'need for treatment' are particularly contested in the United States, and the prospect of incorporating consumer perspectives into service planning (and thereby offering legitimacy to public views on need for care) may raise the specter of out-of-control costs amongst substance use service system researchers, planners, and payers.

Aside from a lack of subjective measures in research on population need for substance use services, we found that studies measuring subjective need almost always (93%; n = 201) reported one or more objective need estimates as well. Only a minority of studies (38%; n = 61) examined more than one subjective need measure, and only two studies (1%) incorporated all three. Very little research on subjective need was longitudinal in nature or tested hypotheses. Taken together, these findings suggest that the concept of subjective, consumer-defined need for substance use services is conceptually underdeveloped, and more often viewed as a possible analog for objective need, rather than as a construct warranting its own investigation and analysis. Our results also suggest that extant literature in this area has generally avoided efforts to analyze the relationships between perceived need for care, self-assessed barriers to care, and help seeking from family and friends, and the significance of these relationships for understanding the substance use disorder treatment gap.

Inattention to the conceptual aspects of subjective, consumer-defined need may also account for the disparate way in which perceived need for substance use services, self-assessed barriers to service use, and help seeking from friends or family are measured in this literature. Many studies used

simple single item measures of unknown psychometric quality. Critically, 'services' in the context of perceived need and self-assessed barriers was inconsistently defined. Some studies asked participants about need for, or barriers to, 'treatment,' whereas others asked about 'help' instead. This is problematic because the notion of 'treatment' or 'help' may be widely interpreted by different populations. These nonspecific measures may also imply a particular level of intensity (e.g., formal interventions like residential substance use treatment) that participants do not perceive a need for, even if lower intensity or informal supports might have been desirable. Resultantly, estimates of subjective need may vary considerably across studies and populations.

Researchers have developed a range of psychometrically valid instruments to measure the prevalence of problematic substance use and substance use disorders. In contrast, our review indicated that less than ten percent of studies assessing subjective, consumer-defined need used standardized measures. The small proportion of subjective need studies that did adopt standardized measures employed several different types of instruments drawn from both the general mental health and substance misuse literatures. Given the availability of an array of instruments, it remains unclear as to why more research on subjective need has not employed these, or other standardized measures. Further study is required to investigate the suitability of new and existing standardized instruments for measuring subjective need for substance use services at the population level.

Methodological and measurement weaknesses demonstrated in our review may be attributable to the disciplinary diversity inherent in prioritizing consumer perspectives on population need for substance use services. Research on diagnosis and classification of mental health and substance use disorders in the community is traditionally conducted within the purview of psychiatric epidemiology.

However, whereas epidemiologists are concerned with understanding prevalence, correlates, and etiological factors underlying disease, health services researchers are primarily focused on examining system features and other factors that predict service use (Regier, Shapiro, Kessler, & Taube, 1984). Neither of these disciplinary traditions has attended to subjective perceptions with the same enthusiasm as psychosocial research, which focuses on assessing individuals' perspectives on treatment need in relation to psychosocial factors. Given the diversity of these disciplinary perspectives, the present results suggest that the concept of subjective need has fallen through the cracks in research conducted on population need for substance use services.

Disciplinary diversity may also explain why so few studies measuring perceived need have used the resulting data to actually estimate system capacity required to meet population need for substance use services. We identified only one such study in our review (McAuliffe et al., 1991). Unlike health services research, epidemiological or psychosocial research traditions typically do not prioritize service system planning. While it is unrealistic to expect all substance use survey research to directly inform system planning, it can be argued that research measuring disorder prevalence and service utilization has the implicit aim of providing relevant data for increasing uptake into care for people requiring services. Indeed, most perceived need studies incorporated estimates of substance use disorder prevalence and service utilization, and many of these studies were population-based. This suggests that at least some of the literature on perceived need has the potential to inform system planning. An outstanding task for health services researchers is to attempt to convert these data into required service capacity estimates for a given jurisdiction. Ideally this exercise will generate knowledge useful for improving system planning, and informing future epidemiological and psychosocial research designed to

improve the validity and utility of survey instruments of perceived need.

Strengths and limitations of this review

This scoping review offers a critical analysis of 35 years of research on population need for substance use services. It is the first review of its kind to assess the extent to which subjective, consumer-derived need measures are incorporated into this literature, and to assess existing methodological and measurement approaches to studying subjective need for substance use services. While our review was comprehensive, we limited our scope to substance use disorders and did not assess studies focused on general mental health. This decision is justifiable as many jurisdictions plan substance use services separately from other mental healthcare, and a large body of research is dedicated specifically to substance use disorders and related services. However, several articles in our review included prevalence estimates for other mental disorders and associated service use. It is possible that some of our analysis is relevant for understanding the role of subjective measures in the broader literature on population need for mental health services; but we cannot state this definitively. As we excluded some studies because of their focus on HIV prevention rather than on substance use services *per se*, research assessing population need for harm reduction services is likely to be underrepresented here. We focused on peer-reviewed, English literature and thus inevitably missed studies published in other languages and possibly in the grey literature.

We coded for the presence of both objective and subjective estimates of need for care, but we did not assess of the quality of this evidence nor characterize how these variables were treated in each study. We also provide no synthesis of the comprehensive empirical findings of objective need studies. These all remain tasks of a future systematic review. EH conducted the full-text screen of all included

articles independently, which may have introduced some bias. We attempted to mitigate this bias by ensuring other authors were consulted and a consensus was reached in ambiguous cases.

Conclusion

A large volume of research over the past thirty-five years has addressed population need for substance use services, and scholarship in this area has grown exponentially over the past decade. Contemporaneously, in the United States and elsewhere, there been a growing receptivity to consumer voices in mental healthcare practice and policymaking. Deinstitutionalization and the shift toward community-based care has enabled consumers to play a larger role in their own treatment decisions and to advocate collectively to improve services, and change policies (Tomes, 2006). Yet despite growth in research on population need for substance use services, and mainstreaming of consumer perspectives in some aspects of mental healthcare, research in this area generally downplays consumer perspectives, both in quantifying population need for services, and in actual service system planning. This knowledge gap challenges our ability to predict service utilization and improve uptake into substance use services. Meaningful incorporation of consumer perspectives into research on population need for substance use services is overdue, and we have identified several ways to address this task. Concerted interdisciplinary research efforts are needed to refine the concept of subjective need, examine relationships between its constituent constructs, and psychometrically validate and standardize new or adapted measurement instruments. Future health services research should also evaluate approaches for incorporating subjective need measures to enhance estimates of required service system capacity. In the absence of these efforts, the potential for subjective measures of need to provide further insight into the substance use disorder treatment gap, and mitigate morbidity and mortality of substance misuse, will remain

untapped.

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Chapter 3: Perceived unmet need and barriers to care amongst street-involved people who use illicit drugs

Abstract

Purpose. Research on perceived unmet need for care for mental health and substance use problems focuses on general populations to the detriment of hidden populations. This study describes prevalence and correlates of perceived unmet need for care in a community-based sample of street-involved people who use illicit drugs; and identifies barriers to care.

Methods. A sample of 320 street-involved people who use drugs, residing in a mid-sized Canadian city, participated in a structured, interviewer-assisted survey. The survey included the Perceived Need for Care Questionnaire, which assessed unmet need for care for mental health and substance use problems across seven service types. Logistic regression examined the associations between perceived unmet need, extent of socioeconomic marginalization, and problem severity. Barriers associated with unmet service needs were also examined.

Results. 263 participants (82%) reported unmet need for one or more services during the past year. Odds of reporting one or more unmet needs were elevated amongst participants reporting substantial housing instability, (adjusted odds ratio [AOR]= 2.37; 95 % confidence interval [CI]: 1.19-4.28) and among participants meeting criteria for drug dependence (AOR = 1.22; 95 % CI: 1.03-1.50), even after adjustment for sociodemographic covariates. Structural barriers, rather than motivational barriers, were the most commonly reported reasons for unmet service needs.

Conclusion. Street-involved people who use drugs experience very high rates of perceived unmet need for care for mental health and substance use problems. General population studies on perceived unmet need are insufficient for understanding needs and barriers to care in hidden populations.

Introduction

A disconcerting proportion of people experiencing mental health and/or substance use problems do not access appropriate care including treatment, counseling, and other related health and social services. Population-based surveys conducted in North America and Western Europe demonstrate that 35-50 % of people meeting criteria for mental and substance use disorders do not access care [1–3]. Further, the presence or absence of a diagnosable mental health or substance use disorder influences – but does not solely determine – whether or not care will be sought [4–7], because not all people who meet objective criteria for mental and/or substance use disorders perceive that they need care, or experience sufficient disability to warrant intervention [8,9]. Those who do perceive a need for care, but do not have this need met, report considerably higher levels of disability and distress, which tend to improve once care needs are met [3,10].

A number of recent studies have attempted to identify subpopulations that are most likely to perceive unmet service needs [3,9,11–20]. Findings from general population surveys indicate that perceived unmet need for care is positively associated with socioeconomic marginalization [9,11,15,19] and problem severity [3,13,17-20]. Additionally, females [14,15,20], younger adults [3,11,17-20] and some ethnic minority groups [12,14,16,17] experience greater perceived unmet service needs.

Research in this area has also identified a number of potentially significant barriers to care experienced by those reporting unmet service needs [17,19,21–24]. Several studies reported that motivational or attitudinal barriers —such as a desire to self-mange one's own symptoms —are the most common reasons underlying unmet care needs [3,18,19,20, 21,23-25]. Structural barriers related to costs or system access issues tend to be less frequently reported across populations and disorders, with the exception of a few studies [13,17] from the

United States, where access to health care has been historically more contingent on a patient's ability to afford services or sufficient insurance coverage.

Extant research facilitates greater understanding of who is more likely to perceive unmet need for care for mental health and substance use problems, and provides useful information for system planners attempting to predict service demand, and/or develop strategies for enhancing service uptake [7]. However, this research emphasizes perceived need for care and unmet service needs in general populations [1,8,27]. Relatively few studies have systematically examined perceived unmet needs in hidden populations (e.g., people who are homeless, street-involved, institutionalized, or sex workers), primarily because telephone and internet-based sample frames used in general population surveys typically exclude individuals without access to these technologies. Although several epidemiological studies have generated estimates of service needs for hidden populations using disorder prevalence measures [28–33], relatively few studies focus on measuring perceived unmet need for care for mental health and substance use problems amongst hidden populations. Two recent studies of perceived unmet need amongst homeless people reported elevated rates of unmet need for mental health care [34,35]. Socioeconomic marginalization [35] and problem severity [34] were also associated with unmet needs. However, a gap in epidemiological research exists – we identified no studies systematically assessing perceived need, service use, unmet service need, and self-assessed barriers to care for mental health or substance use problems in a street-involved population of people who use illicit drugs (PWUD).

Despite this paucity of research, Bijl and Ravelli have suggested that estimates of perceived unmet need derived from general population surveys do not diverge considerably from those generated from hidden populations [15]. This assertion has yet to be empirically examined, however. Because street-involved PWUD experience disproportionate levels of

substance use and mental health problems and are at risk for related negative health and social outcomes [36–42], at least some of this disproportionate burden of disease may be attributable to unmet needs for care for mental health and substance use problems. Thus, our first research objective was to describe perceived unmet service need amongst street-involved PWUD.

Street-involved PWUD tend to experience high rates of socioeconomic marginalization, unemployment, and problem severity as compared with non-street involved people [43,44]. However, a number of studies have documented heterogeneity in this population including important gradients in housing status [36,45–47] and severity of substance use problems [48–51]. These findings suggest that *extent* of socioeconomic marginalization and problem severity may be associated with higher rates of unmet service need, even within street-involved populations. This issue has also not been tested empirically. Thus, our second research objective was to examine whether correlates of unmet need found in general populations, particularly extent of socioeconomic marginalization and problem severity, also predict perceived unmet service need amongst street-involved PWUD. Our final research objective was to examine whether motivational or structural barriers to care for mental health and substance use problems are more commonly reported by street-involved populations of PWUD.

Method

Sample

We recruited a community-based convenience sample of street-involved PWUD who were not currently attending specialty mental health or addiction treatment from April – October 2014 [in a mid-sized Canadian city]. A trained peer outreach worker with knowledge of the local street drug scene recruited study participants using street outreach and snowball sampling techniques. Recruitment occurred in and around three inner city agencies (two with embedded needle exchange programs) serving vulnerable populations. Study eligibility included

regular, self-reported illicit drug use over the past six months (at least once per month), and immersion in the local street drug scene (two or more days per week spent in the inner city). Additionally, participants had to be at least 15 years of age. We excluded participants who were acutely intoxicated or appeared to lack the cognitive capacity to understand and complete the informed consent process. Of 324 participants initially enrolled in the study, we excluded four individuals due to delayed onset of acute intoxication, leaving a total of 320 study participants. We provided a twenty-dollar (CAD) cash honorarium to individuals who participated in the survey. The Health Research Ethics Board at [Authors' University] approved our study protocol.

Measures

Participants completed an interviewer-assisted structured survey that took, on average, 50 minutes to complete.

Independent variables. We assessed problem severity with the Drug Use Disorders Identification Test (DUDIT) [52,53], a validated, standardized clinical screen assessing presence of problematic substance use and drug dependence. Men scoring six or more, and women scoring two or more, on the DUDIT met criteria for problematic substance use. Respondents scoring 25 or higher on the DUDIT were classified as being drug dependent. We assessed socioeconomic marginalization using self-reports of perceived housing instability [1 (very stable) - 5 (very unstable)], and transitory sleeping (1 = reported sleeping in ≥ 6 different places during the previous six months; 2 = reported sleeping in 5 or fewer different places during the previous six months).

Dependent variable. We used an adapted version of the Perceived Need for Care Questionnaire (PNCQ) [54,55], a reliable and validated instrument designed for community-based samples, to measure past-year unmet service needs. We asked participants: "In the past 12 months, have you received [SERVICE] because of problems with your emotions, mental

health, or use of alcohol or drugs?" and repeated the question for each of seven categories of service including: information; medication; hospitalization; counselling; social interventions (help sorting out problems with money or housing); skills training (help to improve ability to work or take care of oneself); and harm reduction (services to reduce health risks associated with substance use). Participants could respond: "no I did not need this kind of help [no need]," "yes in the past 12 months, and I got enough service as I needed [served]," "yes in the past 12 months and I did not get as much service as I needed [underserved]," or '"no, but I think I needed this kind of help in last 12 months [unserved]." We classified all participants reporting unserved or underserved needs for one or more of the seven target services as having *unmet need for care*. Additionally, we used this question series to assess whether or not participants had 'perceived need' for services [e.g., were served, underserved, or unserved] and whether or not participants had any 'service use' [e.g., were served and underserved].

Barriers to care. The PNCQ also examines self-assessed barriers to care amongst participants who report unmet care needs, but has not been previously employed to study care needs amongst street-involved or other hidden populations. We suspected it might not sufficiently measure unique barriers to care experienced by the target population. As such, we adapted the list of reasons included in the PNCQ, in consultation with inner city mental health and substance use service providers. Possible responses included four motivational barriers (I do not want help at this time, I prefer to manage on my own, I did not think anything would help, I was afraid to ask for help or what others would think of me); and five structural barriers (I did not know where to get help, I could not afford it, I asked for help but did not receive it, the waitlist was too long or no spaces available, I was only allowed a limited amount of help). Participants could endorse more than one reason underlying unmet service needs in each of the seven service categories.

We also permitted participants to specify 'other' unlisted reasons, which were recorded verbatim by the interviewer. We then coded verbatim reasons into motivational or structural barrier categories as appropriate.

Covariates. Additional measures included sex, age, and racial minority status (classified as self-reported Aboriginal status).

Statistical Analyses

First, descriptive statistics (percentages, means) and appropriate bivariate analyses (χ^2 tests, t-tests) compared participants reporting and not reporting perceived unmet need for one or more services in relation to each independent variable (perceived housing instability [mean score]); transitory sleeping [yes; no]; and drug dependence [yes; no]) as well as the study covariates (mean age, sex [female; male]; and Aboriginal status [yes; no]. Next, logistic regression analyses modeled the odds of perceived unmet need for one or more services as a function of the independent variables. An initial analysis examined associations with our independent variables; this was followed by a second logistic regression analysis, which adjusted for potential effects of the study covariates (age, sex, and Aboriginal status). Finally, we calculated the proportion of participants reporting different reasons for having partially or fully unmet care needs. We analyzed barriers across different service categories as well as for specific services. We used SPSS version 22.0 for all analyses and a significance level of <0.05.

Results

Sample Description

Of 320 study participants, 206 (65 %) were male, 202 (65 %) identified as Aboriginal; most were middle-aged with a mean age±SD of 42±11. The sample was street-involved: 290 (91 %) reported spending most of each day in the inner city, 182 (57 %) reported either 'a little

unstable' or 'very unstable' housing, and 136 (42 %) indicated that they had slept in more than six different places in the past six months. Frequent illicit substance use was common: 247 (77 %) participants reported using drugs four or more times per week, and 279 (91 %) reported injecting illicit drugs in the past six months. All but one participant met criteria for problematic substance use, and 181 (62 %) met criteria for drug dependence.

Unmet Service Needs

Overall, 307 participants (96 %) perceived a need for care for mental health or substance use problems in the year preceding data collection, and 303 (95 %) indicated receiving one or more services in the previous 12 months. Nevertheless, 263 participants (82 %) reported unmet need for one or more services during the past year. Given the exceptionally high rate of unmet need across services, we also examined unmet need for care for each service.

Table 3-1. Perceived unmet need for care for mental health or substance use problems in the past year amongst a sample of 320 street-involved PWUD (N = 320).[a]

Perceived unmet need by service type	Sex				Age	Aboriginal Status				Drug Dependence[c]				Housing Instability[d]	Transitory Sleeping[e]			
	Male		Female			Yes		No		Yes		No			Yes		No	
	n	%	n	%	M±SE	n	%	n	%	n	%	n	%	M±SE	n	%	n	%
Any unmet need[b]																		
Unmet need	168	81.6	94	83.2	41.6 ± .6	165	81.7	94	84.7	159	88.3	83	74.1	3.5 ± .1	118	86.8	145	78.8
No unmet need	38	18.4	19	16.8	41.9 ± 1.5	37	18.3	17	15.3	21	11.7	29	25.9	2.8 ± .2	18	13.2	39	21.1
Social interventions																		
Unmet need	120	58.3	70	61.9	41.8 ± .7	116	57.4	70	63.1	116	64.4	60	53.6	3.8 ± .1	91	66.9	99	53.8
No unmet need	86	41.7	43	38.1	41.5 ± .5	86	42.6	41	36.9	64	35.6	52	46.4	2.8 ± .2	45	33.1	85	46.2
Counselling																		
Unmet need	92	44.7	60	53.1	40.9 ± .8	99	49.0	60	54.1	103	57.2	36	32.1	3.7 ± .1	79	58.1	73	39.7
No unmet need	114	55.3	53	46.9	42.4 ± .8	103	51.0	51	45.9	77	42.8	76	67.9	3.2 ± .1	57	41.9	111	60.3
Medication																		
Unmet need	67	32.5	41	36.3	40.2 ± 1.0	63	31.2	42	37.8	75	41.7	29	25.9	3.6 ± .2	52	38.2	56	30.4
No unmet need	139	67.5	72	63.7	41.1 ± 1.1	139	68.8	69	62.2	105	58.3	83	74.1	3.3 ± .1	84	61.8	128	69.6
Skills training																		
Unmet need	66	32.0	34	30.1	41.2 ± .9	64	31.7	34	30.6	68	37.8	27	24.1	3.7 ± .2	53	39.0	47	25.5
No unmet need	140	68.0	79	69.9	41.9 ± .7	138	68.3	77	69.4	112	62.2	85	75.9	3.3 ± .1	83	61.0	137	74.5
Information																		
Unmet need	49	23.8	40	35.4	41.1 ± 1.1	57	28.2	29	26.1	52	28.9	32	28.6	3.7 ± .2	45	33.1	44	23.9
No unmet need	157	76.2	73	64.6	41.9 ± .6	145	71.8	82	73.9	128	71.1	80	71.4	3.3 ± .1	91	66.9	140	76.1
Hospital care																		
Unmet need	37	18.0	19	16.8	39.5 ± 1.3	31	15.3	25	22.5	41	22.8	12	10.7	4.1 ± .2	33	24.3	24	13.0
No unmet need	169	82.0	94	83.2	42.2 ± .6	171	84.7	86	77.5	139	77.2	100	89.3	3.2 ± .1	103	75.7	160	87.0
Harm reduction																		
Unmet need	20	9.7	15	13.3	38.0 ± 1.7	21	10.4	13	11.7	19	10.6	11	9.8	4.1 ± .2	19	14.0	16	8.7
No unmet need	186	90.3	98	86.7	42.1 ± .6	181	89.6	98	88.3	161	89.4	101	90.2	3.3 ± .1	117	86.0	168	91.3

[a] Percentages calculated by column.
[b] Unmet need for one or more services.
[c] Drug dependence classified as scoring ≥ 25 on the Drug Use Disorders Identification Test (DUDIT)
[d] Possible scores range from 1 (very stable) to 5 (very unstable).
[e] Transitory sleeping classified as sleeping in ≥ 6 or more different places in previous 6 months.

Social interventions (190; 59 %) and counseling (152; 47 %) were the two service categories with the highest levels of perceived unmet need. Table 3-1 summarizes the characteristics of individuals who did and did not report unmet service needs. Participants who reported unmet need for one or more services were more likely than those reporting no unmet service needs to meet criteria for drug dependence ($\chi 2=9.85$, df=1, p=.002) and to report higher housing instability (t=-3.10, df=318, p=.002). We observed a similar pattern amongst participants reporting unmet need for counseling, however, these participants were also more likely to report transitory sleeping ($\chi^2=10.63$, df=1, p=.001). Conversely, participants reporting unmet need for social interventions were more likely to report higher housing instability (t=-5.36, df=318, p<.001) and transitory sleeping ($\chi^2=5.57$, df=1, p=.018), but not drug dependence ($\chi^2=3.41$, df=1, p=.065). There were no significant differences in sex, age, or Aboriginal status between participants reporting unmet need for care, and those reporting no unmet service needs.

Correlates of Unmet Service Need

Meeting criteria for drug dependence was associated with more than double the odds (adjusted odds ratio [AOR]=2.37) of experiencing unmet need for one or more services (Table 3-2). These odds were also elevated (AOR=1.22) for every unit increase on our 5-point scale of perceived housing instability. For social interventions, odds of having perceived unmet need were significantly greater amongst those with increased housing instability (AOR=1.38). Conversely, for perceived unmet need for counseling, drug dependence was the strongest predictor (AOR=2.49). Adjustment for age, sex, and racial minority status did not significantly impact any of these results.

Table 3-2. Logistic regression analyses of predictors of perceived unmet need for care among street-involved PWUD (N = 320).

	Any unmet need for services				Unmet need for social interventions				Unmet need for counselling			
	Model 1: Predictors		Model 2: Adjusted for covariates		Model 1: Predictors		Model 2: Adjusted for covariates		Model 1: Predictors		Model 2: Adjusted for covariates	
	OR	95% CI	AOR	95% CI	OR	95% CI	AOR	95% CI	OR	95% CI	AOR	95% CI
Independent variables												
Housing instability[a] (mean score)	1.24*	1.03 – 1.50	1.22*	1.00 – 1.49	1.38**	1.19 – 1.61	1.38**	1.19 – 1.62	1.10	.96 – 1.28	1.08	.93 – 1.26
Transitory sleeping[b] (1 = no; 2 = yes)	1.26	.63 – 2.53	1.26	.61 – 2.60	1.18	.70 – 1.99	1.28	.74 – 2.21	1.66*	1.00 – 2.74	1.57	.93 – 2.64
Drug dependence[c] (1 = no; 2 = yes)	2.26*	1.19 – 4.28	2.37*	1.22 – 4.59	1.28	.77 – 2.13	1.21	.72 – 2.05	2.47**	1.49 – 4.11	2.49**	1.48 – 4.18
Covariates												
Age (in years)		-	1.00	.97 – 1.03		-	1.02	.99 – 1.05		-	.99	.97 – 1.03
Sex (1 = Male; 2 = Female)		-	1.10	.54 – 2.27		-	1.52	.87 – 2.67		-	1.21	.71 – 2.08
Aboriginal status (1 = no; 2 = yes)		-	.716	.35 – 1.45		-	.71	.41 – 1.23		-	.96	.57 – 1.62

*p<.05, **p<.01

[a]Possible scores range from 1 (very stable) to 5 (very unstable).

[b]Transitory sleeping classified as sleeping in ≥ 6 or more different places in previous 6 months.

[c] Drug dependence classified as scoring ≥ 25 on the Drug Use Disorders Identification Test (DUDIT).

Table 3-3**.** Self-reported reasons for perceived unmet need for care calculated across services, for social interventions, and for counseling in the past year amongst a sample of street-involved PWUD (N=320).[a]

	Reasons for unmet need across all services (n = 939)		**Reasons for unmet need for social interventions only** (n = 254)		**Reasons for unmet need for counseling only** (n = 195)	
	n	%	n	%	n	%
Motivational barriers						
I do not want help at this time	173	18.4	24	9.4	53	27.2
I prefer to manage on my own	109	11.6	12	9.8	30	15.4
I did not think anything would help	31	3.3	6	2.4	7	3.6
I was afraid to ask for help or what others would think of me	30	3.2	4	1.6	10	5.1
Structural barriers						
I was only allowed a limited amount of [service]	179	19.1	68	26.8	11	5.6
I asked for help but did not receive it	116	12.4	61	24.0	11	5.6
I did not know where to get help	95	10.1	18	7.1	21	10.8
The waitlist was too long or there were no spaces available	92	9.8	52	20.5	21	10.8
I was not satisfied with care received or it was poor quality[b]	68	7.2	2	.8	13	6.7
I could not afford it	35	3.7	2	.8	13	6.7
Other[c]	11	1.2	1	.4	5	2.6

[a] Total number of barriers reported across seven service categories by participants with fully or partially unmet needs was 939. Participants could specify more than one reason for unmet need for any service.

[b] Additional reason added after analysis of participants' verbatim 'other' responses.

[c] Includes verbatim reasons that could not be classified under one of the above reasons.

Barriers to Care

The 263 participants reporting a perceived unmet need for one or more services reported 939 barriers to care (Table 3-3). Overall, more participants reported structural barriers to care (64 %) than motivational or attitudinal barriers (37 %). The most common reason for unmet need for one or more services was 'only allowed a limited amount of care' followed by 'not wanting help at this time.' Reasons cited for unmet need for social interventions were most commonly structural, including 'only being allowed a limited amount of service' (27 %) and 'asking for help but not receiving it' (24 %). Conversely, the majority of reasons cited for unmet need for counseling were motivational, including 'do not want help at this time' (27 %) and 'preferring to manage on my own' (15 %).

Discussion

To our knowledge, this is the first study that describes perceived need, unmet service need, and barriers to care for mental health and substance use problems amongst street-involved PWUD. Our objectives were to describe prevalence of unmet need in this population; examine the extent to which social marginalization and problem severity (factors that predict perceived unmet need for services in general populations) also predict unmet need amongst street-involved PWUD; and describe self-assessed barriers to care in this population.

Virtually all participants in our sample met criteria for problematic drug use or drug dependence, and almost all perceived a need for, and used, one or more services for reasons of mental health and substance use in the previous year. These results are striking in relation to previous studies that reported only 10-30 % of individuals with substance use disorders in the general population perceived a need for services, and fewer still accessed services [10,18,56,57]. We also observed very

high rates of perceived unmet service need; 82 % of participants reported unmet need for one or more services. In comparison, using a single-item measure of perceived unmet service need, Rush et al. (2010) reported that only 13 % of Canadian adults in the general population who met criteria for a substance use disorder perceived an unmet need for care [18]. This disparity in unmet need between the present sample and the general population is likely not attributable to differences in measurement, as Meadows & Burgess also reported much lower rate (21 %) of perceived unmet need for services amongst Australian adults who met diagnostic criteria for substance use disorder in the general population using the PNCQ [10]. In that study, as with our sample, need for social interventions was least likely to be met.

In terms of predictors of unmet need, we found that increased socioeconomic marginalization (housing instability) and problem severity (drug dependence) were associated with increased odds of experiencing unmet need for one or more services. However, problem severity did not predict unmet need for social interventions, and social marginalization was not associated with unmet need for counseling. This implies that different factors may underlie unmet need across different kinds of services and that single-item measures of perceived unmet need for services, commonly used in this literature, may mask some of this complexity. Additionally, unlike previous research conducted with general populations, [3,11,12,14-20] in our study, rates of unmet need across services, for social interventions, or for counseling, did not differ significantly by sex, age, or racial minority status. These results suggest that if particular sub-populations of street-involved PWUD experience higher rates of unmet need for care, they are likely not distinguishable by demographic characteristics only.

Unlike findings reported from general populations, [3,18-21,23,25] our sample of street-involved PWUD endorsed structural barriers to care more frequently than motivational barriers. In contrast, Urbanoski et al. [3] reported that only 21 % of Canadians with substance use disorder cited structural

barriers as the main reason for experiencing perceived unmet need for care. These results suggest that even in a country with universal access to healthcare and a range of welfare state entitlements, many street-involved PWUD experience considerable structural disadvantage in their ability to access services for mental health and substance misuse problems.

Our study is preliminary and should be viewed in the context of a number of limitations. By definition, no sampling frame exists for hidden populations. Recruiting representative samples of street-involved PWUD is highly challenging and resource intensive. Our study employed non-probability sampling methods and is therefore not necessarily generalizable to the entire population of street-involved PWUD, either locally or in other jurisdictions. Additionally, high service use rates reported by study participants may reflect the fact that we recruited in and around three community agencies, two of which provided health and social services. This may have resulted in an overestimation of service use and potentially an underestimation of unmet need for care, as compared with street-involved PWUD who do not frequent community agencies or their vicinities. Future research adopting a more robust, random design is necessary to corroborate our findings.

The cross-sectional nature of our data do not enable examination of temporal relationships between socioeconomic marginalization, problem severity, and unmet need to determine whether unmet need increases problem severity and marginalization, or if the opposite is true. Previous research on drug use and homelessness suggests that these relationships may be complex and bi-directional [58–60], however, untangling the causal pathways between perceived unmet need for care and its predictors remains an important task for longitudinal research on street-involved PWUD.

We relied on self-report data to assess unmet need, service use, and barriers to care for mental health and substance use problems. Asking participants to recall care episodes and perceptions of need

over a 12-month period may be problematic from a measurement perspective, particularly amongst street-involved PWUD. Nevertheless, most studies of perceived need for care adopt this time frame; and it thus enabled comparisons between our sample and results obtained in general population surveys [3]. Finally, perceived need is not the same as objective or expert-assessed need for care for mental health and substance use problems. As such, our findings risk overestimating need for care amongst our sample. However, as other researchers have noted, perceived unmet need for care is strongly associated with higher levels of disability and distress, thus even subclinical cases reporting unmet need may still warrant intervention [3,10,17].

Conclusion

Notwithstanding these limitations, our study demonstrated the feasibility of measuring consumer perspectives on unmet service needs and barriers to care amongst street-involved PWUD. Our findings suggest that this hidden population exhibits much higher rates of perceived need, service use, and unmet need than individuals with substance use disorders in the general population. Additionally, although we found that predictors of unmet need for street-involved PWUD were somewhat similar to those found in general populations, barriers to care were markedly different. As such, generalizing findings from general population studies may be inappropriate for fully understanding and mitigating unmet need amongst street-involved populations. Future research should investigate how socioeconomic marginalization and problem severity interact to produce unmet need and barriers to care, and investigate causal factors explaining the co-occurrence of high rates of service use and high levels of unmet need. Researchers and policymakers internationally have scaled up efforts to better understand and mitigate the large treatment gap that exists for mental health and substance use problems. To ensure health equity, and avoid potentially widening existing disparities in mental health

and substance use care, these research and intervention efforts should also attend to the needs of street-involved PWUD and other socially marginalized hidden populations [7].

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Chapter 4: Conclusion

Globally, misuse of alcohol and other drugs is a growing cause of noncommunicable disease burden, and morbidity and mortality attributable to substance misuse (SM) and substance use disorders (SUDs) are particularly high amongst people who are socioeconomically marginalized (Galea & Vlahov, 2002). Despite the availability of a variety of effective interventions for reducing substance use and improving health and social functioning (Babor, 2015), 150 million people worldwide are living with SUDs (Whiteford, Ferrari, Degenhardt, Feigin, & Vos, 2015), and international data demonstrate that at least 35-50% of them do not access services for these problems (Demyttenaere et al., 2004).

Consistent findings of a large SUD treatment gap and emerging scholarship on a public health approach to substance use have stimulated conceptual, theoretical, and empirical work on substance use service systems (Babor, 2015). This work emphasizes shortcomings of normative service planning approaches—widely used in Canada and other countries—which base resource allocation decisions and system-wide planning mainly on stakeholder consultation, political advocacy, and shifting funding priorities (Pirkis, Harris, Buckingham, Whiteford, & Townsend-White, 2007). As a result, substance use services are often uncoordinated and implemented haphazardly, and systems overemphasize provision of specialized treatment services designed for individuals with the most severe and complex needs (Rush, Tremblay, Fougere, Perez, & Fineczko, 2014). This is problematic because the majority of people experiencing SM and SUDs do not require such highly specialized and costly care, though they may require a variety of lower intensity services and supports (Rush et al., 2014).

Needs-based planning approaches have developed in response to these challenges. These approaches adopt tiered frameworks as a tool for planning comprehensive service systems that incorporate a wide set of general and specialty health and social service settings, and provide supports appropriate for meeting population needs across varying levels of SM and SUD problem severity (Rush, 2014).

Implementing evidence-informed, needs-based approaches requires population data on the number of people needing substance use services, and levels of problem severity in the population. Relevant research that directly estimates population need via community-based surveys has become increasingly common over the past two decades (Minoletti et al., 2012). This research has mainly adopted an objective, expert-determined perspective on population need for services, focused on estimating diagnostic prevalence of SUDs. Yet this focus on objective estimates of need is questionable in light of growing evidence that, even after accounting for indicators of problem severity, diagnostically-assessed need for care is only modestly predictive of actual service use; many severe cases do not seek services, and most people in treatment are mild or sub-threshold cases that do not meet clinical criteria for SUDs (Demyttenaere et al., 2004). Therefore, objective, expert-determined estimates of need (i.e., prevalence of substance use, SUDs and service utilization) may be necessary, but are not sufficient for substance use service system planning.

The limitations associated with using objective measures to estimate service need likely arise because need is socially negotiated and at least partially subjective (Slade, 1994). Deinstitutionalization of mental health and substance use services coincided with the development of service delivery models explicitly conceptualizing patients as active and autonomous participants in their care (Tomes, 2006). This conceptualization is reinforced by Andersen's (1995) influential model of health services utilization, which highlights consumers' subjective views on their own service needs as a significant proximal determinant of actual service use. Research incorporating subjective, consumer-defined need measures (including perceived need for services, self-assessed barriers to service use, and help-seeking from family and friends) has provided useful insights on the SUD treatment gap; it has improved our ability to understand why some individuals seek out services, when others do not. For example, evidence demonstrates that only 10-30 percent of individuals who meet diagnostic criteria for SUDs in the general population perceive a need for care (Rush, et al. 2010; Meadows & Burgess, 2009; Mojtabai & Crum, 2013). Moreover, motivational rather than structural barriers to service use are more frequently cited as reasons for unmet service needs in the general population (Nelson &

Park, 2006). These and other insights have led many to argue that research on objective, expert-determined need should be complemented with subjective, consumer-defined need estimates, since the latter have the potential to provide a more complete understanding of population service need (Ritter, Chalmers, & Sunderland, 2013).

Despite the promise of shifting from normative to needs-based system planning, no previous reviews have systematically mapped the literature on population need for substance use services and the extent to which it incorporates expert and consumer perspectives. No research has analyzed current approaches to studying subjective need, and the potential for this research to inform substance use service planning. This is problematic because the implicit aim of research on population need for services is to provide relevant data for improving planning and resource allocation, and ultimately increase uptake into appropriate interventions.

Another gap in the literature on population need for substance use services relates to socially marginalized, hidden populations. Although several epidemiological studies have generated estimates of objective need for substance use services amongst these groups (Fazel, Khosla, Doll, & Geddes, 2008), fewer studies have assessed their subjective needs. In particular, very little research has examined subjective need amongst street-involved people who use drugs (PWUD). Of the subjective need studies conducted with this population, the majority measure perceived need for, or self-assessed barriers to, either generic substance use 'treatment' (Phillips, et al., 2014; Weschsberg, et al., 2009; Wood, et al., 2005) or one specific type of substance use service (e.g., syringe exchange, methadone programs) only (Maher, et al., 2001; Al-Tayyib & Koester, 2011; Ti, et al., 2011; Todd, et al., 2008). Few studies have measured subjective need across a variety of substance use service types. Additionally, no research has examined perceived need, perceived unmet need, and self-assessed barriers to a variety of substance use services amongst street-involved people who use drugs (PWUD).

In light of these knowledge gaps, and in an effort to advance the literature on population need for substance use services, this dissertation had two broad objectives: (1) to systematically describe and map the literature on population need for substance use services, and (2) describe consumer perceptions of service

need among marginalized, street-involved PWUD.

To address these objectives, Study 1 consisted of a systematic scoping review of the literature on population need for substance use services (i.e., general health and social services, and specialty substance use and mental health care) that included an assessment of 1930 full-text articles. In Study 2, structured surveys measuring service needs for substance use and mental health problems were conducted with a sample of 320 street-involved PWUD. The remainder of this concluding chapter summarizes the main findings and limitations of each study, considers avenues for future research, and identifies potential policy implications.

Main findings

Findings from Study 1 indicate that research on population need for substance use services is growing exponentially, and over 600 studies have been published since 2010 alone. The vast majority of this research (96%; n = 1534) prioritized objective, expert-determined estimates of need for SM and SUD services. A much smaller proportion (14%; n =217) reported data on subjective, consumer-defined need measures. This disparity is somewhat surprising given the theoretical and practical potential of consumer perspective studies, outlined above. Amongst subjective need studies, only a minority (38%; n = 61) examined more than one subjective need measure, and only two studies (1%) incorporated all three. Very little subjective need research tested hypotheses or was longitudinal in nature. Overall, it appears that the construct of subjective need for substance use services is conceptually underdeveloped because rather than receiving its own investigation and analysis, it is more often treated as a possible analog for objective need.

Inattention to theoretical conceptualization of subjective, consumer-defined need may explain measurement weaknesses also observed in this literature. Many studies use simple single item measures. 'Services' in the context of perceived need and self-assessed barriers have been variously defined. Some studies ask participants about need for, or barriers to 'treatment,' whereas others ask about 'help' instead. Consistently defining 'services' is critical, because the notion of 'treatment' or 'help' could be widely

interpreted by different populations. These nonspecific measures may also imply a particular level of intensity (e.g., residential substance use treatment) that participants may not perceive a need for, even if lower intensity supports would have been acceptable. Study 1 also demonstrated that less than 10% of articles used standardized instruments to measure subjective service need. Finally, with regard to utility for substance use service system planning, Study 1 identified only one article that incorporated data on subjective need to estimate the service system capacity required to meet population need for substance use services. However, several studies (n = 106) measuring perceived need also reported estimates of diagnostic prevalence and service utilization, suggesting these studies could hypothetically be used to inform substance use service system planning.

Study 1 was the first of its kind to consider the extent to which subjective, consumer-defined perspectives are incorporated into the literature on population need for substance use services, and provides a useful assessment of existing methodological and measurement approaches to studying subjective need for substance use services. Yet the findings from Study 1 should be considered in the context of their limitations. Although the scoping review criteria were comprehensive, they did not include articles focused on general mental health only (e.g., excluding SUDs or SM). Some Study 1 findings may be relevant for understanding the role of subjective measures in the broader literature on population need for mental health services; but this cannot be stated definitively. This review also excluded studies published in languages other than English or in the grey literature, meaning some relevant research was likely missed. All included articles were coded for the presence of both objective and subjective need estimates, but the review did not assess the quality of each study, characterize how these variables were treated, or provide a comprehensive synthesis of empirical findings.

Study 2 addressed some of the measurement shortcomings identified in the Study 1, by providing systematic estimates of subjective need for services for substance use and mental health problems amongst a sample of 320 street-involved PWUD. The survey incorporated Meadows, Harvey, Fossey, & Burgess's (2000)

psychometrically validated Perceived Need for Care Questionnaire (PNCQ), which measures perceived need for services, perceived unmet need, met need, and self-assessed barriers across seven different general health and social services categories. All but one study participant met criteria for problematic substance use, and 62% (n = 181) met criteria for drug dependence. Additionally, just over half of all participants reported unstable housing.

Overall, study participants reported very high rates (96%; n = 307) of perceived need, and service use (95%; = 303) in the previous 12 months. Although almost all participants perceived a need for care and accessed related services, 82% (n = 263) reported unmet need for one or more services during the past year. Participants reported experiencing the highest levels of unmet need for social interventions (59%; n = 190 [i.e., help to sort out problems with money or housing]) and counselling (47%; n = 152). Increased socioeconomic marginalization and problem severity were associated with higher odds of experiencing perceived unmet need for one or more services, overall. However, problem severity did not predict unmet need for social interventions, and socioeconomic marginalization was not associated with unmet need for counselling. Finally, participants were more likely to report structural barriers to one or more services (64% of total barriers cited). 'I was only allowed a limited amount of services' was the most common barrier reported. However motivational barriers, such as 'I do not want help at this time' were the main self-assessed reason cited for unmet need for counselling.

Study 2 is the first research to systematically describe perceived need, perceived unmet need, and self-assessed barriers to a variety of substance use services amongst street-involved PWUD, and its findings highlight the potential for subjective need studies to improve understanding of the substance use disorder treatment gap amongst this population. While insightful, Study 2 findings should be viewed as preliminary. Our study employed non-probability sampling methods and is therefore not necessarily generalizable to the entire population of street-involved PWUD, either locally or in other jurisdictions. The high service use rates reported by study participants may reflect the fact that they were recruited in and around three community agencies,

two of which provided health and social services. Service use rates may be overestimated in this study and unmet need for care may be underestimated, as compared with other PWUD who do not frequent community agencies or their vicinities. Further research adopting a more robust, random design is necessary to corroborate our findings. Although exploring temporal relationships between perceived unmet need for care and its predictors would provide useful insights on the substance use disorder treatment gap, the cross-sectional nature of Study 2 data do not enable this examination. Study 2 data on service needs, service use and barriers were all self-reported. Asking participants to recall care episodes and perceptions of need over a 12-month period may be problematic from a measurement perspective, although this is time frame adopted by most studies and it thus enabled comparisons between our sample and results obtained in general population surveys.

Beyond these individual study shortcomings, some general limitations should also be noted. This dissertation has focused on consumer perspectives on service need, an understudied area within the literature on population need for substance use services. This focus is not intended to imply that there are not important conceptual and methodological debates in research on objective, expert-defined need worthy of further study. In particular, additional research is needed to further refine existing objective need measures and enhance their overall utility for service planning. Another promising research avenue is conceptual work designed to further clarify the underlying reasons for why some people meet criteria for substance use disorders (including severe cases), but do not perceive a need for services, while others perceive a need and report considerable distress but do not meet diagnostic criteria, and the potential implications for refining understanding of both objective and subjective need.

Considerations for future research

Measurement issues

Taken together, the above findings imply that different factors both predict and underlie perceived

unmet need across various kinds of substance use services, and that a large proportion of extant research (employing single item, and/or generic measures of subjective service need) may not be capturing this complexity. Generating effective strategies to mitigate perceived unmet need and barriers to service use may be contingent on developing and/or implementing instruments capable of capturing subjective need across a variety of substance use service categories.

Meadows et al.'s (2000) PNCQ is one such instrument; and was the most frequently implemented standardized tool in the subjective need research reviewed in Study 1. As Study 2 demonstrates, implementing the PNCQ with a sample of street-involved PWUD is feasible. Further research should focus on formally adapting and validating this instrument for use with street-involved PWUD, and other socially marginalized, hidden populations (e.g., homeless people; sex workers). Even if it is formally validated for use with these populations, the PNCQ currently only measures service need across seven categories of general health and social services. Ideally, standardized instruments should be capable of assessing subjective service need for both general and specialized (e.g., residential treatment programs; medically supervised detoxification services; supported living arrangements) substance use and mental health care. Although the large volume of existing substance use services and supports could make developing such an instrument challenging, studies capturing subjective needs across both specialty and general services would greatly facilitate needs-based planning efforts, and contribute to the development of service systems capable of effectively meeting a variety of population needs.

Conceptual issues

Despite the promising potential of subjective, consumer-defined need research to inform system planning, Study 1 identified only one survey research article that used perceived need data to calculate the system capacity required to meet population need. This research assessed perceived need amongst the Rhode Island general adult population to estimate the required number of residential substance use treatment beds, but did not consider need for other types of substance use services (McAuliffe, Breer, Ahmadifar, & Spino,

1991). An outstanding task for health services research on substance use services systems is to take existing data on perceived need to estimate additional system capacity requirements. Further work is also necessary to devise models that incorporate data on perceived need to inform the planning of both high and low intensity services, and estimate service system capacity required to meet needs in both general and hidden populations.

More broadly, there is a need to systematically review the empirical findings of subjective need studies. Study 1 scoped the literature on population need for substance use services, assessed the proportion that incorporates subjective need measures, and characterized existing methodological and measurement approaches. However, no research has attempted a systematic or meta-analytic review of empirical findings from subjective need studies. In particular, research systematically reviewing the literature on perceived need for services, self-assessed barriers to care, and help-seeking from family and friends to identify consistent predictors and outcomes of these variables is required. This kind of synthesis would provide valuable information on how subjective need measures are treated in extant research (e.g., as outcomes, correlates, predictors, or controls), and enable an assessment of the quality of existing evidence. It would also facilitate further conceptual and theoretical development of subjective, consumer-defined need, by outlining the main conclusions advanced in this literature, describing what is known about the relationships between subjective need variables, and highlighting areas in need of further study. A systematic review of subjective need studies would also facilitate research comparing the importance of consumer perceptions of need relative to other theorized determinants of help seeking. Study 1 lays the groundwork for this research, as it provides a large and systematically compiled dataset of subjective need studies, however it also raises a potential caution. The finding that subjective need has been measured and studied inconsistently in the literature on population need for substance use services, implies that a systematic review may not be feasible at this time.

This dissertation raises questions regarding how high rates of perceived unmet need can coincide with high rates of service use amongst street-involved PWUD. There are a number of possible explanations for this discrepancy. General health and social services may be fairly accessible, but otherwise have limited capacity to

fully meet the needs of street-involved PWUD, particularly those with drug dependence. Alternatively, services may have sufficient capacity, but not sufficient quality, to satisfy perceived needs. Longitudinal, qualitative, and quantitative research is needed to further investigate the phenomenon of high perceived unmet need amongst socially marginalized service users, test the validity of different explanatory hypotheses, and develop strategies for improving the ability of existing services to better satisfy perceived unmet needs amongst this population.

Research on subjective, consumer-defined estimates of need has the potential to provide new insights on the substance use disorder treatment gap, generate avenues of investigation that could result in mitigation of unmet need and barriers in the short term, and help improve health outcomes in the long term. Although consumer perspectives have been integrated into some aspects of mental health services (Tomes, 2006), research on population need for substance use services generally downplays consumer perspectives, both in quantifying population need for services, and in actual service system planning.

This inattention to consumer perspectives may be in part attributable to the disciplinary diversity inherent in measuring subjective need for substance use services. Research on diagnosis and classification of mental health and substance use disorders in the community is traditionally conducted within the purview of psychiatric epidemiology. However, epidemiologists are primarily concerned with understanding prevalence, correlates, and etiological factors underlying disease. Health services research has also been conducted on substance use services but tends to focus on understanding system features and other factors that predict service use (Regier, Shapiro, Kessler, & Taube, 1984). Neither of these traditions has prioritized subjective perceptions as enthusiastically as psychosocial researchers who have focused on assessing individuals' perspectives on service need in relation to various psychosocial factors. The concept of subjective need may have fallen through the cracks implied by the diversity of these disciplinary perspectives. Future research on population need for substance use services should adopt a multidisciplinary approach in an effort to build on and integrate these diverse perspectives, and advance and refine the construct of subjective, consumer-defined need.

Policy and practice implications

Findings from Study 2 suggest that street-involved PWUD experience much higher rates of perceived need, service use, and perceived unmet need as compared with individuals in the general population. For example, (Rush et al., 2014) reported that only 13% of Canadians who meet criteria for SUDs perceive an unmet service need; and Meadows & Burgess (2009), in an Australian study utilizing the PNCQ, found that 21% of adults meeting criteria for SUDs had perceived unmet need. Study 2 also documented that structural barriers were more common amongst street-involved PWUD, although this varied across service categories. In contrast, epidemiological research has consistently documented that motivational, rather than structural, barriers are more frequently cited as reasons for unmet need amongst members of general populations. Taken together these comparisons imply that it is likely not sufficient to generalize findings from general population studies to understand the service needs of socially marginalized, hidden populations. Service system planners should attend to the service needs of both target populations when allocating resources and planning substance use service system capacity. Most general adult surveys of population need do not currently capture socially marginalized, hidden populations; therefore, a concerted effort is required to build ongoing monitoring systems that target both hidden and general populations.

Policymakers, governments, and non-governmental organizations routinely fund survey research to generate representative population-level estimates of mental health and substance use service need. These studies are often funded with the explicit aim of providing data relevant data for substance use service system planning. As the concept of subjective, consumer-defined need is further developed and refined, these regional and national surveys should also evolve. In particular, funders could direct research teams to implement standardized measures of subjective need across multiple substance use service categories. This would likely generate better estimates of population need, and enhance jurisdiction's capacity to plan their service systems. Integrating subjective need estimates into population-based surveys would also be consistent with trends toward meaningful inclusion of patient perspectives in substance use and mental health care (Tomes, 2006).

Conclusion

Robust research on consumer perspectives within the literature on population need for substance use services is overdue. An emergent public health approach is taking research on substance use services out of clinic and into the community, and considering ways to improve service systems and generate population-level health impacts (Babor, Stenius, & Romelsjo, 2008). This trend presents an opportunity to develop a strong tradition of consumer perspectives scholarship that synthesizes existing interdisciplinary theoretical and empirical work, and sets new directions for research on population need and substance use service systems. Other areas of public health scholarship—e.g., research on HIV/AIDS (Blankenship, Friedman, Dworkin, & Mantell, 2006)—have already achieved success integrating epidemiological, health services, and psychosocial disciplinary perspectives to understand and mitigate major health threats. There is potential to learn from these experiences and gain valuable insight for leveraging consumer perspectives to improve service systems and achieve positive health outcomes at a population level. The implications of a strong public health approach to substance use in general, and research on population need for services in particular, should not be underestimated. Just as several decades of research on substance use services have improved our ability to manage SM and SUD, concerted efforts to align service systems with population need have the potential to translate into significant reductions in morbidity and mortality globally.

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Appendices

Appendix 1: Database-specific controlled vocabularies

Ovid MEDLINE® In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE®

1. substance-related disorders/ or exp alcohol-related disorders/ or amphetamine-related disorders/ or cocaine-related disorders/ or drug overdose/ or inhalant abuse/ or marijuana abuse/ or exp opioid-related disorders/ or phencyclidine abuse/ or psychoses, substance-induced/ or substance abuse, intravenous/ or exp substance withdrawal syndrome/ or exp street drugs/
2. ((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or mari#uana or cannabis or hash* or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) adj3 (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*)).ti,kf.
3. (illicit drug* or illicit substance* or illegal drug* or illegal substance* or street drug* or needle exchange* or syringe exchange or safe injection or supervised injection).ti,kf.
4. 1 or 2 or 3
5. *"health services needs and demand"/ or *needs assessment/ or *Health Services Accessibility/
6. (need or needs or barrier*).ti.
7. ((service* or resource* or care or treatment or facilit* or hospital* or rehab* or harm reduction) adj3 (need or needs or access* or demand* or availab* or barrier*)).ab,kf.
8. ((unmet or perceive*) adj2 need*1).ab,kf.
9. *Health Resources/ or *Resource Allocation/
10. *Health Planning/ or exp *Regional Health Planning/
11. planning.ti. or ((plan* or allocat*) adj5 (service* or resource* or facilit*)).ab,kf.
12. or/5-11
13. 4 and 12
14. (ep or sd or td or ut or ec or og).fs.
15. *forecasting/ or models, statistical/ or models, theoretical/ or epidemologic factors/ or linear models/ or logistic models/ or (linear regression or capture recapture).ti,ab,kf.
16. regression analysis/ or (logistic regression or regression analysis or representative sampl* or prevalence or survellance).ti,ab,kf.
17. Health Surveys/ or Questionnaires/
18. (national or global or regional or state wide or statewide or province wide or nationwide or nation wide or country wide or countrywide).ti,ab,kf.
19. Population Surveillance/ or Population/
20. Demography/ or (demograph* or sociodemograph*).ti,ab,kf.
21. data collection/
22. ("National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or global burden or burden of disease).ti,ab,kf.
23. (longitudinal or prospective or retrospective or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds).mp.
24. model*.ti.
25. or/14-24
26. 13 and 25

27. (estimat* and (prevalence or acces* or utili* or population or service*)).ti.
28. (estimat* adj3 (prevalence or acces* or utili* or population or service*)).ab,kf.
29. 27 or 28
30. 4 and 29
31. 26 or 30
32. limit 31 to (english language and yr="1980 -Current")
33. remove duplicates from 32

Ovid EMBASE
1. addiction/ or alcoholism/ or withdrawal syndrome/
2. exp drug dependence/ or "drug dependence treatment"/
3. street drug/
4. ((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or mari#uana or cannabis or hash* or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) adj3 (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*)).ti.
5. (illicit drug* or illicit substance* or illegal drug* or illegal substance* or street drug* or needle exchange* or syringe exchange or safe injection or supervised injection).ti.
6. or/1-5
7. needs assessment/ or "health care need"/ or health care access/ or health care availability/
8. (needs or needs or barrier*).ti.
9. ((service* or resource* or care or treatment or facilit* or hospital* or rehab* or harm reduction) adj3 (need or needs or access* or demand* or availab* or barrier*)).ab.
10. ((unmet or perceive*) adj2 need*1).ab.
11. health care planning/
12. resource allocation/
13. planning.ti. or ((plan* or allocat*) adj5 (service* or resource* or facilit*)).ab.
14. or/7-13
15. 6 and 14
16. "prediction and forecasting"/ or computer prediction/ or forecasting/ or prediction/
17. "population and population related phenomena"/ or population/ or population model/ or population research/ or population risk/ or rural population/ or suburban population/ or susceptible population/ or urban population/ or vulnerable population/
18. process model/ or mathematical model/ or statistical model/ or theoretical model/
19. exp regression analysis/
20. (logistic regression or regression analysis or representative sampl* or prevalence or survellance).ti,ab.
21. health survey/
22. exp questionnaire/
23. data collection method/ or questionnaire/
24. demography/
25. (demograph* or sociodemograph*).ti,ab.
26. ("National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or global burden or burden of disease).ti,ab.
27. (longitudinal or prospective or retrospective or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds).ti,ab.
28. (national or global or regional or state wide or statewide or province wide or nationwide or nation wide or

country wide or countrywide).ti,ab.
29. model*.ti.
30. or/16-29
31. 15 and 30
32. (estimat* and (prevalence or acces* or utili* or population or service*)).ti.
33. (estimat* adj3 (prevalence or acces* or utili* or population or service*)).ab.
34. 32 or 33
35. 6 and 34
36. 31 or 35
37. limit 36 to (english language and yr="1980 -Current")
38. remove duplicates from 37

Ovid PsycInfo
1. exp drug abuse/
2. exp drug dependency/
3. addiction/ or exp alcoholism/ or exp drug addiction/
4. drug withdrawal/ or alcohol withdrawal/ or detoxification/
5. drug rehabilitation/ or exp alcohol rehabilitation/ or sobriety/ or exp twelve step programs/
6. ((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or mari#uana or cannabis or hash* or nicotine or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) adj3 (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*)).ti,ab,id.
7. (illicit drug* or illicit substance* or illegal drug* or illegal substance* or street drug* or needle exchange* or syringe exchange or safe injection or supervised injection).ti,ab,id.
8. "Drug & Alcohol Rehabilitation ".cc.
9. "Substance Abuse & Addiction ".cc.
10. or/1-9
11. needs assessment/ or health service needs/ or utilization reviews/
12. (need or needs or barrier*).ti.
13. ((service* or resource* or care or treatment or facilit* or hospital* or rehab* or harm reduction) adj3 (need or needs or access* or demand* or availab* or barrier*)).ab,id.
14. ((unmet or perceive*) adj2 need*1).ab,id.
15. exp Health Care Utilization/
16. health care services/ or health care seeking behavior/ or help seeking behavior/
17. resource allocation/
18. planning.ti. or ((plan* or allocat*) adj5 (service* or resource* or facilit*)).ab,id.
19. or/11-18
20. 10 and 19
21. prediction/
22. exp estimation/
23. models/
24. population/ or "population (statistics)"/ or demographic characteristics/
25. surveys/ or data collection/ or questionnaires/
26. exp multivariate analysis/
27. exp statistical regression/
28. (national or global or regional or state wide or statewide or province wide or nationwide or nation wide or country wide or countrywide).ti,ab,id.

29. (logistic regression or regression analysis or representative sampl* or prevalence or survellance or linear regression or capture recapture).ti,ab,id.
30. (demograph* or sociodemograph*).ti,ab,id.
31. ("National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or global burden or burden of disease).ti,ab,id.
32. (longitudinal or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds).mp.
33. (model* or estimat*).ti.
34. or/21-33
35. 20 and 34
36. limit 35 to (english language and yr="1980 -Current")
37. remove duplicates from 36

Ovid All EBM [Evidence-Based Medicine] Reviews (Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, Database of Abstracts of Reviews of Effect, Health Technology Assessment Database and Economic Evaluation Database)
1. substance-related disorders/ or exp alcohol-related disorders/ or amphetamine-related disorders/ or cocaine-related disorders/ or drug overdose/ or inhalant abuse/ or marijuana abuse/ or exp opioid-related disorders/ or phencyclidine abuse/ or psychoses, substance-induced/ or substance abuse, intravenous/ or exp substance withdrawal syndrome/ or exp street drugs/
2. ((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or mari#uana or cannabis or hash* or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) adj3 (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*)).ti,ab,kf.
3. (illicit drug* or illicit substance* or illegal drug* or illegal substance* or street drug* or needle exchange* or syringe exchange or safe injection or supervised injection).ti,ab,kf.
4. 1 or 2 or 3
5. "health services needs and demand"/ or needs assessment/ or Health Services Accessibility/
6. (need or needs or barrier*).ti.
7. ((service* or resource* or care or treatment or facilit* or hospital* or rehab* or harm reduction) adj3 (need or needs or access* or demand* or availab* or barrier*)).ab,kf.
8. ((unmet or perceive*) adj2 need*1).ab,kf.
9. Health Resources/ or Resource Allocation/
10. Health Planning/ or exp Regional Health Planning/
11. planning.ti. or ((plan* or allocat*) adj5 (service* or resource* or facilit*)).ab,kf.
12. or/5-11
13. 4 and 12
14. (ep or sd or td or ut or ec or og).fs.
15. forecasting/ or models, statistical/ or models, theoretical/ or epidemologic factors/ or linear models/ or logistic models/ or (linear regression or capture recapture).ti,ab,kf.
16. regression analysis/ or (logistic regression or regression analysis or representative sampl* or prevalence or survellance).ti,ab,kf.
17. Health Surveys/ or Questionnaires/
18. (national or global or regional or state wide or statewide or province wide or nationwide or nation wide or country wide or countrywide).ti,ab,kf.
19. Population Surveillance/ or Population/

20. Demography/ or (demograph* or sociodemograph*).ti,ab,kf.
21. data collection/
22. ("National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or global burden or burden of disease).ti,ab,kf.
23. (longitudinal or prospective or retrospective or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds).mp.
24. model*.ti.
25. or/14-24
26. 13 and 25
27. (estimat* and (prevalence or acces* or utili* or population or service*)).ti.
28. (estimat* adj3 (prevalence or acces* or utili* or population or service*)).ab,kf.
29. 27 or 28
30. 4 and 29
31. 26 or 30
32. limit 31 to (english language and yr="1980 -Current")
33. remove duplicates from 32

EBSCO CINAHL Plus with Full-text
S1 (MH "Substance Use Disorders") OR (MH "Alcohol Withdrawal Syndrome+") OR (MH "Substance Withdrawal Syndrome+") OR (MH "Substance Dependence+") OR (MH "Substance Abuse, Intravenous") OR (MH "Inhalant Abuse") OR (MH "Alcohol-Related Disorders+") OR (MH "Substance Abuse") or ((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or marijuana or marihuana or cannabis or hash* or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) n3 (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*)) OR ("illicit drug*" or "illicit substance*" or "illegal drug*" or "illegal substance*" or "street drug*" or "needle exchange*" or "syringe exchange" or "safe injection" or "supervised injection")
S2 (MH "Health Services Needs and Demand+") OR (MH "Needs Assessment") OR (MH "Health Services Accessibility+") OR (MH "Health Resource Utilization") OR (MH "Health Resource Allocation") OR (MH "Health and Welfare Planning") OR (MH "Health Facility Planning") OR (MH "National Health Programs") OR (MH "State Health Plans") OR (MH "Strategic Planning+") OR TI (need or needs or barrier* or planning) OR ((service* or resource* or care or treatment or facilit* or hospital* or rehab* or "harm reduction") n3 (need or needs or access* or demand* or availab* or barrier*)) OR ((unmet or perceive*) n2 (need or needs)) OR ((plan* or allocat*) n5 (service* or resource* or facilit*))
S3 S1 AND S2
S4 (MH "Forecasting") OR (MH "Models, Statistical") OR (MH "Models, Theoretical") OR (MH "Regression+") OR (MH "Surveys") OR (MH "Population Surveillance") OR (MH "Questionnaires") OR (MH "Structured Questionnaires") OR (MH "Demography") OR (MH "Geographic Factors") OR (MH "Population+") OR (MH "Data Collection") OR (regression or "capture recapture" or "representative sampl*" or prevalence or survellance) OR (national or global or regional or "state wide" or statewide or "province wide" or nationwide or "nation wide" or "country wide" or countrywide or demograph* or sociodemograph*) OR ("National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or "global burden" or "burden of disease") OR (longitudinal or prospective or retrospective or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds) OR TI model*
S5 S3 AND S4

S6 TI (estimat* and (prevalence or acces* or utili* or population or service*)) OR AB (estimat* n3 (prevalence or acces* or utili* or population or service*))
S7 S1 AND S6
S8 S5 OR S7
Limiters - Published Date: 19800101-20151231

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(TITLE ((substance OR drug* OR alcohol*) AND (abus* OR addict* OR dependen* OR misus* OR withdrawal OR overdose* OR detox* OR user*)) OR TITLE (cocaine OR meth OR methamphetamine OR amphetamine OR crack OR heroin OR opiate* OR opioid* OR narcotic* OR morphine OR marijuana OR marihuana OR cannabis OR hash* OR lsd OR hallucinogen* OR inhalant* OR oxycodon* OR vicodin OR codeine OR fentanyl OR "illicit drug*" OR "illicit substance*" OR "illegal drug*" OR "illegal substance*" OR "street drug*" OR "needle exchange*" OR "syringe exchange" OR "safe injection" OR "supervised injection")) AND (TITLE (need OR needs OR barrier* OR planning) OR TITLE-ABS-KEY ((service W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (resource* W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (care W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (treatment W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (facilit* W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (hospital* W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*))) OR TITLE-ABS-KEY ((unmet W/2 (need OR needs)) OR (perceive* W/2 (need OR needs)) OR (plan* W/5 (service* OR resource* OR facilit*)) OR ("harm reduction" W/3 (need OR needs OR access* OR demand* OR availab* OR barrier*)) OR (allocat* W/5 (service* OR resource* OR facilit*)))) AND (TITLE-ABS-KEY (forecast* OR regression OR population OR questionnaire* OR demograph* OR sociodemograph* OR regression OR "capture recapture" OR "representative sampl*" OR prevalence OR survellance OR national OR global OR regional OR "state wide" OR statewide OR "province wide" OR nationwide OR "nation wide" OR "country wide" OR countrywide OR "National Epidemiologic Survey on Alcohol and Related Conditions" OR nesarc OR "National Survey on Drug Use and Health" OR nsduh OR nlaes OR "National Drug and Alcoholism Treatment Utilization Survey" OR ndatus OR "global burden" OR "burden of disease" OR longitudinal OR prospective OR retrospective OR cross sectional OR cohort OR algorithm* OR methodolog* OR multivaria* OR predictor* OR indicator* OR odds) OR TITLE (model*)) OR (TITLE-ABS-KEY (substance OR drug* OR alcohol* OR cocaine OR meth OR methamphetamine OR amphetamine OR crack OR heroin OR opiate* OR opioid* OR narcotic* OR morphine OR marijuana OR marihuana OR cannabis OR hash* OR lsd OR hallucinogen* OR inhalant* OR oxycodon* OR vicodin OR codeine OR fentanyl) AND TITLE-ABS-KEY (abus* OR addict* OR dependen* OR misus* OR withdrawal OR overdose* OR detox* OR user*) OR TITLE ("illicit drug*" OR "illicit substance*" OR "illegal drug*" OR "illegal substance*" OR "street drug*" OR "needle exchange*" OR "syringe exchange" OR "safe injection" OR "supervised injection") AND TITLE (estimat* AND (prevalence OR acces* OR utili* OR population OR service*)) OR ABS (estimat* W/3 (prevalence OR acces* OR utili* OR population OR service*))) AND (LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005) OR LIMIT-TO (PUBYEAR , 2004) OR LIMIT-TO (PUBYEAR , 2003) OR LIMIT-TO (PUBYEAR , 2002) OR LIMIT-TO (PUBYEAR , 2001) OR LIMIT-TO (PUBYEAR , 2000) OR LIMIT-TO (PUBYEAR , 1999) OR LIMIT-TO (PUBYEAR , 1998) OR LIMIT-TO (PUBYEAR , 1997) OR LIMIT-TO (PUBYEAR , 1996) OR LIMIT-TO (PUBYEAR , 1995) OR LIMIT-TO (PUBYEAR , 1994) OR LIMIT-TO (PUBYEAR , 1993) OR LIMIT-TO (PUBYEAR , 1992) OR LIMIT-TO (PUBYEAR , 1991) OR LIMIT-TO (PUBYEAR , 1990) OR LIMIT-TO (PUBYEAR , 1988) OR LIMIT-TO (PUBYEAR , 1987) OR LIMIT-TO (PUBYEAR , 1986) OR LIMIT-TO (PUBYEAR , 1985) OR LIMIT-TO (PUBYEAR , 1984) OR LIMIT-TO (PUBYEAR , 1980))

Web of Science Core Collection

#1 TI=((substance or drug* or alcohol* or cocaine or meth or methamphetamine or amphetamine or crack or heroin or opiate* or opioid* or narcotic* or morphine or marijuana or marihuana or cannabis or hash* or lsd or hallucinogen* or inhalant* or oxycodon* or vicodin or codeine or fentanyl) AND (abus* or addict* or dependen* or misus* or withdrawal or overdose* or detox* or user*) or "illicit drug*" or "illicit substance*" or "illegal drug*" or "illegal substance*" or "street drug*" or "needle exchange*" or "syringe exchange" or "safe injection" or "supervised injection")

#2 TI=(need or needs or barrier* or planning) OR TS=((service* or resource* or care or treatment or facilit* or hospital* or rehab* or “harm reduction”) near/3 (need or needs or access* or demand* or availab* or barrier*) OR (unmet or perceive*) near/2 (need or needs) OR (plan* or allocat*) near/5 (service* or resource* or facilit*))

#3 #1 AND #2

#4 TS=(forecast* or regression or population or questionnaire* or demograph* or sociodemograph* or regression or "capture recapture" or "representative sampl*" or prevalence or survellance or national or global or regional or "state wide" or statewide or "province wide" or nationwide or "nation wide" or "country wide" or countrywide or "National Epidemiologic Survey on Alcohol and Related Conditions" or nesarc or "National Survey on Drug Use and Health" or nsduh or NLAES or "National Drug and Alcoholism Treatment Utilization Survey" or NDATUS or "global burden" or "burden of disease" or longitudinal or prospective or retrospective or cross sectional or cohort or algorithm* or methodolog* or multivaria* or predictor* or indicator* or odds) or TI=(model*)

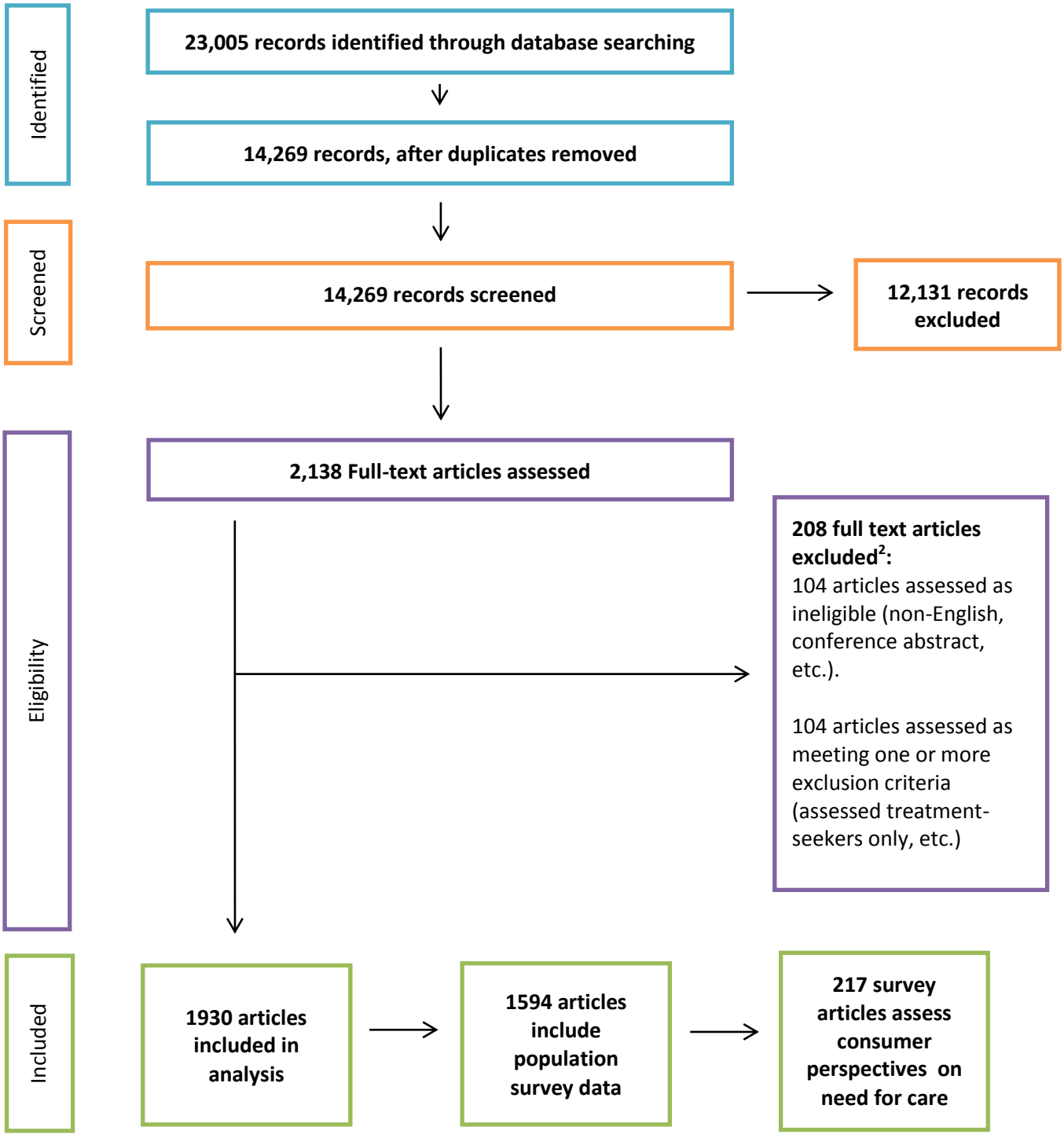
#5 #3 AND #4

#6 TS=(estimat* near/3 (prevalence or acces* or utili* or population or service*))

#7 #1 AND #6

#8 #5 OR #7

Appendix 2: Systematic search strategy flow diagram [1]



Notes:

[1] Adapted from PRISMA 2009 Flow Chart (Moher, Liberati, Tetzlaff, Altman, The PRISMA Group, 2009).

[2]208 full text articles excluded for the following reasons: assessed treatment-seekers only (n = 56); focus on general health status or other health problem (e.g., need for HIV care) (n = 28); mental health only, excludes substance use (n = 3); non-empirical, not relevant to assessment of need (n = 2); did not assess population need directly (e.g., survey of administrators opinions on need) (n = 6); intervention study (n = 9); non-English (n = 14); not a journal article (e.g., commentary) (n = 17); full text could not be retrieved (n = 73)

Appendix 3. Coding framework

All studies				
Year	**Year Published**	Year the study/article was published	Format = YYYY	
Study Location	**Single Country**	Is the data presented in the study from only one country? For non-empirical articles, treat as single country and specify the home country of the lead author in the next field.	0 = No 1 = Yes	
	Specify Country	Specify either the single country in which the data were collected, or the home country of the lead author for non-empirical articles. Code the country's global region in the next field	String variable- write in country name	
	Country classification	Specify whether the single country is high income, or low-middle income	1 = High income 2 = Low income	Determined according to World Bank classification system http://data.worldbank.org/about/country-and-lending-groups
	Specify Country Region	Code the global region of the single country where the data were collected	1 = North America (Canada & US) 2 = Europe 3 = Australia and Oceania 4 = Latin America and Caribbean 5 = Africa 6 = Middle East 7 = Asia	1. North America = Canada and US (including Puerto Rico) 2. Europe = all countries in the European Union and Albania, Andorra, Belarus, Bosnia, Croatia, Faroe Islands, Gibraltar, Guerney and Alderney, Iceland, Jersey, Kosovo, Liechtenstein, Macedonia, Man, Island of, Moldova, Monaco, Montenegro, Norway, Russia, San Marino, Serbia, Svalbard and Jan Mayan Islands, Switzerland, Turkey, Ukraine, Vatican City State (Holy See). 3. Australia and Oceania Australia = Fiji, French Polynesia, Guam, Kiribati, Marshall Islands, Micronesia, New Caledonia, New Zealand, Papua New Guinea, Samoa, Samoa (American), Solomon Islands, Tonga, Vanuatu 4. Latin America and Caribbean = Mexico, South America, Central America, and Caribbean countries 5. Africa = All countries on the African continent 6. Middle East = Bahrain, Iraq, Iran, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, United Arab Emirates, Yemen

				7. Asia = Afghanistan, Armenia, Azerbaijan, Bangladesh, Bhutan, Brunei Darussalam, Cambodia, China, Georgia, Hong Kong, India, Indonesia, Japan, Kazakhstan, North Korea, South Korea, Kyrgyzstan, Laos, Macao, Malaysia, Maldives, Mongolia, Myanmar (ex-Burma), Nepal, Pakistan, Philippines, Singapore, Sri Lanka (ex-Ceilan), Taiwan, Tajikistan, Thailand, Timor Leste (West), Turkmenistan, Uzbekistan, Vietnam 8. Multiple regions = data are from 2 or more of the regions listed above
	Multiple Countries	Is the data presented in the study from more than one country? [Not applicable for non-empirical articles] Specify region (rather than countries) in the next field.	0 = No 1 = Yes	For studies where data were collected in more than one country
	Specify Multiple Countries' Region	Code the global region where the data were collected, or select 'multiple regions' if the data were collected from country's spanning more than one. This field is only for studies where data were collected in multiple countries.	1 = North America (Canada & US) 2 = Europe 3 = Australia and Oceania 4 = Latin America and Caribbean 5 = Africa 6 = Middle East 7 = Asia 8 = Multiple regions (two or more of the regions listed above)	1. North America = Canada and US 2. Europe = all countries in the European Union and Albania, Andorra, Belarus, Bosnia, Croatia, Faroe Islands, Gibraltar, Guerney and Alderney, Iceland, Jersey, Kosovo, Liechtenstein, Macedonia, Man, Island of, Moldova, Monaco, Montenegro, Norway, Russia, San Marino, Serbia, Svalbard and Jan Mayen Islands, Switzerland, Turkey, Ukraine, Vatican City State (Holy See). 3. Australia and Oceania Australia = Fiji, French Polynesia, Guam, Kiribati, Marshall Islands, Micronesia, New Caledonia, New Zealand, Papua New Guinea, Samoa, Samoa (American), Solomon Islands, Tonga, Vanuatu 4. Latin America and Caribbean = Mexico, South America, Central America, and Caribbean countries 5. Africa = All countries on the African continent 6. Middle East = Bahrain, Iraq, Iran, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, United Arab Emirates, Yemen 7. Asia = Afghanistan, Armenia, Azerbaijan, Bangladesh, Bhutan, Brunei Darussalam, Cambodia, China, Georgia, Hong Kong, India,

				Indonesia, Japan, Kazakhstan, North Korea, South Korea, Kyrgyzstan, Laos, Macao, Malaysia, Maldives, Mongolia, Myanmar (ex-Burma), Nepal, Pakistan, Philippines, Singapore, Sri Lanka (ex-Ceilan), Taiwan, Tajikistan, Thailand, Timor Leste (West), Turkmenistan, Uzbekistan, Vietnam 8. Multiple regions = data are from 2 or more of the regions listed above
Paper type	**Empirical paper**	Is the article empirical or non-empirical?	0 = No 1 = Yes	Non-empirical: Does not present any empirical (quantitative or qualitative) data. Includes articles such as systematic or non-systematic literature reviews (no data analyzed), methods papers (where no data are presented), etc. Empirical: Paper presents quantitative or qualitative data. Includes articles such as quantitative, qualitative or mixed methods studies; systematic reviews; modelling studies; etc.
Data sources	**Biological Data**	Empirical studies only: Does the paper present biological measures of substance use?	0 = No 1 = Yes	Includes articles that present biological data on substance use via individual or aggregate biological samples. E.g., hair analysis, wastewater analysis, urinalysis, etc. **Not mutually exclusive category (e.g., empirical studies can have more than one data source)
	Administrative Data	Empirical studies only: Does the paper analyze/present any administrative data?	0 = No 1 = Yes	Census, area alcohol sales, treatment registers, arrest records, hospital admissions, care episodes, birth registers, Medicare registers, death records, etc. **Not mutually exclusive category (e.g., empirical studies can have more than one data source)
	Qualitative Data	Empirical studies only: Does the article analyze/present any qualitative data?	0 = No 1 = Yes	Includes empirical studies, which present qualitative data (alone or alongside quantitative data). **Not mutually exclusive category (e.g., empirical studies can have more than one data source)
	Population survey Data	Empirical studies only: Does the article analyze/present any population survey research data?	0 = No 1 = Yes	Uses data from direct contact self-reports to estimate population need for services directly. **Not mutually exclusive category (e.g., empirical studies can have more than one data source)
Sampling	**Substance users only**	Survey research studies: Did the survey research study only recruit substance users?	0 = No 1 = Yes	Includes survey research studies in which eligibility was (past month, past year, and/or lifetime) substance use. This includes studies, which

				targeted recruitment to people with alcohol and/or substance use disorders.
Objective need	**Objective need measured**	The survey research examines objective need for substance use services	0 = No 1 = Yes	The survey research study examines objective (expert-defined) need for substance use services. This means assessment of need for services is based on expert (rather than consumer/patient/participant) judgement. Objective need studies contain at least one of the following measures: 1. Substance use prevalence 2. Substance use disorder prevalence 3. Self-reported or objective rates of primary, general, or specialty service utilization 4. Self-reported or objective rates of formal help seeking (e.g., accessing care from primary, generalist, or specialist [health or non-health] professionals). ** Not mutually exclusive (study can examine both objective and perceived need)
Objective need variables	**Substance use prevalence**	Survey research studies: Does the survey research paper report a substance use prevalence estimate?	0 = No 1 = Yes	The survey research provides a substance use prevalence estimate (e.g., % of people in the general or special population reported using one or more licit or illicit substances). [Does not include articles in which entire sample is comprised of substance users] **not mutually exclusive category (e.g., population survey papers can measure more than one need variable.
	Substance use disorder prevalence	Survey research studies: Does the survey research report a substance use disorder prevalence estimate?	0 = No 1 = Yes	The survey research provides an (objective, expert-derived) substance use disorder prevalence estimate. Includes estimates of the proportion of the sample or population who are experiencing: substance dependence, substance abuse, substance use disorder, or addiction. [Includes: binge-drinking; heavy smoking; alcohol problems as these patterns of use may indicate need for substance use services]. **Not mutually exclusive category (e.g., population survey papers can measure more than one need variable.
	Substance use service utilization	Does the survey research report rates of substance use or mental health service use? [One or more general or specialty services;	0 = No 1 = Yes	The survey research provides an estimate of the proportion of the sample that used primary care, general, or specialty services for help with substance use and/or mental health problems. This includes

		includes formal help-seeking]		formal help seeking. **Not mutually exclusive category (e.g., population survey papers can measure more than one objective need variable.
Subjective need measurement	**Subjective need measure**	The survey research incorporates a measure of subjective need for substance use services	0 = No 1 = Yes	The survey research study examines subjective need for substance use services. Consumer perspective studies contain at least one of the following measures: 1. Perceived need or perceived unmet need for care (for substance use or mental health problems) 2. Self-reported rates of help seeking from social networks, friends and family 3. Self-assessed barriers to care. ** Not mutually exclusive (study can examine both objective and subjective need) excludes treatment readiness, hypothetical studies (e.g., if you need treatment would you go to...). Also excludes studies which state that pn was measured but, do not present data from these measures. Examples of pn instruments: Camberwell Assessment of Need, Cardinal Needs Schedule
Subjective need studies				
Study Design	**Cross-sectional design**	Does the study report data from a single cross-sectional or multiple cross-sectional research project?	0 = No 1 = Yes, single cross sectional; 2 = Yes, multiple cross sectional	Cross-sectional: Survey data reported in the study were captured during only one time period, with no follow-up of participants. Multiple cross-sectional: Survey data reported in the study were captured during multiple time periods, but amongst different groups of participants (e.g., participants not followed over time).
	Longitudinal design	Does the study report longitudinal data?	0 = No 1 = Yes	Longitudinal: Survey data reported in the study were captured during multiple time periods, following the same participants over time.
Sample characteristics	**Size of (community-based) sample**	How many participants were included in the study?	Enter number (round to whole number) -9 = mean age unavailable	Aggregate of all samples in multi-site studies Report sample size for community-based proportion only, when available. If not available, report for entire sample. *Report N when available for general population studies*

	Sex of (community-based) participants	Did the study include males, females or both?	0 = Male 1 = Female 2 = Both males and females	Did the study include males, females, or both? If sex is not reported, use gender. If gender is not reported either, code as unavailable. Report demographics for community-based proportion only, when available. If not available, report for entire sample.
	Mean age of (community-based) participants	What was the mean age of participants reported for the single sample, or across multiple samples?	Enter number (round to whole number)	Specify the mean age of participants, rounded to the nearest whole number (e.g., no decimal points). If multiple datasets are analyzed, code the total mean age across datasets (may need to calculate). Report demographics for community-based proportion only, when available. If not available, report for entire sample.
Target population	**General adult population**	Does the survey target the general adult population?	0 = No 1 = Yes	Articles that estimate need for services amongst general adult population (e.g., all adults in one city, state, region, country, etc.)
	Specialty population	Does the survey target a specific specialty population?	0 = No 1 = Yes	Articles that estimate need for services amongst specific special population (e.g., college students, seniors, military personnel, cultural minority groups, etc.)
	Specify the specialty population	Specify the specialty population as described by the authors	Write in description; string variable	E.g., opioid users; crack cocaine smokers, college students, secondary school students, farm workers, etc.
Subjective need measures	**Perceived need**	Does the study estimate whether all or a proportion of the sample or population perceived a need for care for substance use or mental health problems (whether or not this need was met or unmet)? Specify type of measurement in fields below	0 = No 1 = Yes	Does the study estimate the proportion of the sample or population who perceived a need for care for substance use or mental health problems? Includes attempts to measure either perceived need or perceived unmet need for treatment and/or non-treatment seekers in community based samples **not mutually exclusive, e.g., study can estimate more than one perceived need-related variable
	Single Item Perceived Need	For studies, which measure perceived need: Is this variable measured using a single item measure?	0 = No 1 = Yes	E.g., uses one question to measure perceived need Not mutually exclusive (e.g., can be coded single item and 'standardized')
	Multi Item Perceived Need	For studies, which measure perceived need: Is this variable measured using a multi-item index?	0 = No 1 = Yes	E.g., uses more than one question to measure perceived need Not mutually exclusive (e.g., can be coded multi item and 'standardized')

	Standardized Perceived Need	For studies, which measure perceived need: Is this variable measured using a standardized scale or instrument?	0 = No 1 = Yes	E.g., uses a standardized instrument to measure perceived need (e.g., the PNCQ, Camberwell Needs Assessment, etc.) Measure should be coded as multi or single item first, then yes or no for standardized.
	Name of standardized perceived need instrument	For studies in which the measure of perceived need is standardized, specify the name of the instrument	String variable; write in name of instrument	
	Generic or specific service needs	Is perceived need measured for only one generic service category (e.g., mental health treatment, addiction treatment, healthcare for substance problems) or for one or more specific service categories (e.g., counselling, medication, harm reduction, residential treatment, etc.)?	0 = Generic 1 = Specific	Examples of generic service categories include: mental health care, mental health treatment, addiction treatment, etc. Examples of specific service categories include: in-patient treatment, out-patient treatment, counselling, medication, methadone, hospital care, harm reduction services, needle exchange, etc.
	Help-seeking	Does the study estimate the proportion of the sample that sought help for problems with substance use or mental health from family or friends?	0 = No 1 = Yes	Does the study estimate the proportion of the sample that sought help for problems with substance use or mental health from family or friends? Note 'hypothetical' questions about help seeking *if* help is needed are not coded as informal help seeking. **Not mutually exclusive, e.g., study can estimate more than one perceived need-related variable
	Single Item Help-Seeking	For studies, which measure help seeking: Is this variable measured using a single item measure?	0 = No 1 = Yes	E.g., uses one question to measure help-seeking Not mutually exclusive (e.g., can be coded single item and 'standardized')
	Multi Item Help-Seeking	For studies, which measure help seeking: Is this variable measured using a multi-item index?	0 = No 1 = Yes	E.g., uses more than one question to measure help-seeking Not mutually exclusive (e.g., can be coded multi item and 'standardized')
	Standardized Help-Seeking	For studies, which measure help seeking: Is this variable measured using a standardized scale or instrument?	0 = No 1 = Yes	E.g., uses a standardized instrument to measure informal help-seeking Measure should be coded as multi or single item first, then yes or no for standardized.
	Specify name of standardized	For studies in which the measure of informal help-seeking is standardized, specify the name	String variable; write in name of	

	help-seeking instrument	of the instrument	instrument	
	Self-assessed barriers to care	Does the study report participants' self-assessed reasons for being unable to access help for substance use and/or mental health problems?	0 = No 1 = Yes	Does the study report participants' self-assessed reasons for being unable to access help for substance use and/or mental health problems? **Not mutually exclusive, e.g., study can estimate more than one perceived need-related variable
	Single Item Self-assessed Barriers to Care	For studies, which measure self-assessed barriers to care: Is this variable measured using a single item measure?	0 = No 1 = Yes	E.g., uses one question to measure self-assessed barriers to care Not mutually exclusive (e.g., can be coded single item and 'standardized'
	Multi Item Self-assessed Barriers to Care	For studies, which measure self-assessed barriers to care: Is this variable measured using a multi-item index?	0 = No 1 = Yes	E.g., uses more than one question to measure self-assessed barriers to care Not mutually exclusive (e.g., can be coded multi item and 'standardized')
	Standardized Self-assessed Barriers to Care	For studies, which measure self-assessed barriers to care: Is this variable measured using a standardized scale or instrument?	0 = No 1 = Yes	E.g., uses a standardized instrument to measure self-assessed barriers to care (e.g., the PNCQ), Measure should be coded as multi or single item first, then yes or no for standardized.
Analysis	**Specify name of standardized barriers instrument**	For studies in which the measure of self-assessed barriers to care is standardized, specify the name of the instrument	String variable; write in name of instrument	
	Hypothesis testing	Does the perceived need study test one or more explicitly stated hypotheses?	0 = No 1 = Yes	E.g., The authors state hypotheses tested in their analysis and describe whether their findings are or are not consistent with these hypotheses
	Generates estimates	Does the study generate estimates of required services system capacity to meet population need for substance use services?	0 = No 1 = Yes	Does the study use population survey data on perceived need for care to model the required service system capacity to meet population need for substance use services (e.g., how many treatment spaces would be required, how many physician visits would be required, how many people would need counselling, how many people would need brief interventions, etc.?)
	General Health and Social	For studies, which generate estimates: are the estimates for the required capacity of one or	0 = No 1 = Yes	For studies, which generate estimates: are the estimates for the required capacity of one or more general health and social services?

	Services	more general health and social services?		Examples include: primary care, medication, social services, acute or hospital care, harm reduction, skills training, general counselling, etc. **Not mutually exclusive, can estimate more than one type of service
	Specialty addiction and mental health care	For studies, which generate estimates: are the estimates for the required capacity of one or more specialty health and social services?	0 = No 1 = Yes	For studies, which generate estimates: are the estimates for the required capacity of one or more specialty health and social services? Examples include: addiction treatment, opioid dependence treatment, psychiatric hospital care, residential substance use treatment programs, etc. **not mutually exclusive, can estimate more than one type of service

Appendix 4: Subjective, consumer-defined need for services studies identified through systematic scoping review

1. Abagiu, A. O., Cavar, Z., Dannon, P., George, P., Habrat, B., Mahomedy, Z., . . . Kastelic, A. (2014). Outcomes from the International Survey Informing Greater Insights in Opioid Dependence Treatment (INSIGHT) project. *Drugs: Education, Prevention & Policy, 21*(6), 440-450. doi:http://dx.doi.org/10.3109/09687637.2014.945511
2. Al-Tayyib, A. A., & Koester, S. (2011). Injection drug users' experience with and attitudes toward methadone clinics in Denver, CO. *Journal of Substance Abuse Treatment, 41*(1), 30-36. doi:http://dx.doi.org/10.1016/j.jsat.2011.01.009
3. Alam, F., & Barker, P. (2014). Interruption of medication-assisted treatment for opioid dependence: Insights from the UK. *Drugs and Alcohol Today, 14*(3), 114-125. doi:10.1108/DAT-01-2014-0002
4. Alemagno, S. A. (2001). Women in jail: is substance abuse treatment enough? *American Journal of Public Health, 91*(5), 798-800.
5. Ali, M. M., Teich, J. L., & Mutter, R. (2015). The role of perceived need and health insurance in substance use treatment: implications for the affordable care act. *Journal of Substance Abuse Treatment, 54*, 14-20. doi:http://dx.doi.org/10.1016/j.jsat.2015.02.002
6. Andrews, G., Henderson, S., & Hall, W. (2001). Prevalence, comorbidity, disability and service utilisation: Overview of the Australian National Mental Health Survey. *The British Journal of Psychiatry, 178*, 145-153. doi:http://dx.doi.org/10.1192/bjp.178.2.145
7. Arun, P., Chavan, B. S., & Kaur, H. (2004). A Study of reasons for not seeking treatment for substance abuse in community. *Indian Journal of Psychiatry, 46*(3), 256-260.
8. Aveyard, H. (1999). Illicit drug use: information-giving strategies requested by students in higher education. *Health Education Journal, 58*(3), 239-248.
9. Baksheev, G. N., Thomas, S. D., & Ogloff, J. R. (2010). Psychiatric disorders and unmet needs in Australian police cells. *Australian & New Zealand Journal of Psychiatry, 44*(11), 1043-1051. doi:http://dx.doi.org/10.1080/00048674.2010.503650
10. Baldwin, D. M., Brecht, M. L., Monahan, G., Annon, K., Wellisch, J., & Anglin, M. D. (1995). Perceived

need for treatment among pregnant and nonpregnant women arrestees. *Journal of Psychoactive Drugs, 27*(4), 389-399.

11. Barratt, M. J., Cakic, V., & Lenton, S. (2013). Patterns of synthetic cannabinoid use in Australia. *Drug and Alcohol Review, 32*(2), 141-146. doi:http://dx.doi.org/10.1111/j.1465-3362.2012.00519.x
12. Becker, W. C., Fiellin, D. A., Merrill, J. O., Schulman, B., Finkelstein, R., Olsen, Y., & Busch, S. H. (2008). Opioid use disorder in the United States: insurance status and treatment access. *Drug & Alcohol Dependence, 94*(1-3), 207-213. doi:http://dx.doi.org/10.1016/j.drugalcdep.2007.11.018
13. Belenko, S., Lang, M. A., & O'Connor, L. A. (2003). Self-Reported Psychiatric Treatment Needs Among Felony Drug Offenders. *Journal of Contemporary Criminal Justice, 19*(1), 9-29. doi:http://dx.doi.org/10.1177/1043986202239740
14. Bennett, T., & Holloway, K. (2008). Identifying and preventing health problems among young drug-misusing offenders. *Health Education, 108*(3), 247-261. doi:http://dx.doi.org/10.1108/09654280810867114
15. Bennett, T., & Wright, R. (1986). Opioid users' attitudes towards and use of NHS clinics, general practitioners and private doctors. *British Journal of Addiction, 81*(6), 757-763.
16. Benyamina, A. (2014). The current status of opioid maintenance treatment in France: a survey of physicians, patients, and out-of-treatment opioid users. *International journal of general medicine, 7*, 449-457. doi:http://dx.doi.org/10.2147/IJGM.S61014
17. Blitz, C. L., Wolff, N., & Paap, K. (2006). Availability of behavioral health treatment for women in prison. *Psychiatric Services, 57*(3), 356-360.
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