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Short Communication

The Fetal Alcohol Spectrum Disorder and Homelessness Project: Making Connections for Promising Practice

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Abstract

The focus of this brief paper is to describe a current research project exploring the lived experiences of individuals with Fetal Alcohol Spectrum Disorder (FASD) who are supported by the homeless-serving sector in Calgary, Alberta. Individuals with FASD are considered vulnerable due to their disability, which often goes unrecognized and thus viewed as social, emotional and behavioral challenges. It is widely known that individuals with FASD face challenges as a result of brain damage from prenatal alcohol exposure. It is suspected that many individuals with FASD are being served by the Calgary Homeless Foundation's (CHF) frontline agencies without recognition ofthe specialized supports they may need. Our research aims to learn from the experiences of individuals with either diagnosed or suspected FASD who are or have been homeless and from interviews with a wide range of professionals working in the homeless-serving sector regarding their perception of needs and service gaps for this population.

ABBREVIATIONS

FASD: Fetal Alcohol Spectrum Disorder; CHF: Calgary Homeless Foundation; HMIS: Homeless Management Information System

INTRODUCTION

Homelessness describes the situation of an individual or family without stable, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it. It is the result of systemic or societal barriers, a lack of affordable and appropriate housing, the individual/household's financial, mental, cognitive, behavioural or physical challenges, and/or racism and discrimination [1]. Homelessness has grown to astronomical proportions throughout Canada, leading to what has been described as a "national crisis" [2]. In Calgary, homelessness grew by 800% between 1992 and 2008 [3], with the most recent point-in-time count estimating there are approximately 3500 people experiencing homelessness on any given night [4].

A critical area identified as requiring further investigation is in the area of Fetal Alcohol Spectrum Disorder (FASD). There is now robust research exploring the multifaceted and complex nature of homelessness including the unique pathways into homelessness for distinct subpopulations such as youth [5], families [6], Aboriginal peoples [7,8], and women [9,10]. However, an additional sub-group within this chronically homeless population who appear to experience significant challenges in obtaining and maintaining adequate housing is individuals with FASD. Little research has been done in the area of supporting individuals with FASD into sustainable housing and consequently, there is currently limited capacity in programming, trained staff, and knowledge to address the support needs of this population.

The University of Calgary, Faculty of Social Work and the Calgary Homeless Foundation (CHF) have partnered to examine the needs of individuals with FASD who are involved in the homeless-serving sector. In this paper, we present a mixed method, exploratory research study in Calgary, Alberta (2014-2015), which examines the intersection of individuals with FASD and the phenomenon of housing insecurity and homelessness.

BACKGROUND

FASD, referred to as the 'invisible disability', is caused by prenatal alcohol exposure during pregnancy and comes with a significant degree of central nervous system damage, cognitive functioning and secondary disabilities [11]. In the absence of routine, structure, and consistency, individuals with FASD

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struggle. Despite resiliency factors in individuals with FASD, the underlying cognitive impairment caused by prenatal alcohol exposure contributes to their marginalization. As a consequence of their disability, individuals living with FASD often cycle through multiple systems, including homelessness, health [12] and corrections [13].

The primary cognitive issues of FASD contribute to the difficulties of finding sustainable housing and effective supports within the homeless-serving sector. These issues may include difficulties managing time and money, planning, attention deficits, memory issues, and difficulties understanding the consequences of behaviors [14,15]. These issues may all contribute to housing instability as individuals with FASD may not be able to budget their money appropriately or even have funds available and thus may be unable to pay their rent on time. They may miss meetings with their caseworkers or be evicted because of complex behavioral issues.

The relationship between homelessness and the primary and secondary disabilities of FASD is complex. Individual environmental factors associated with increased risk of homelessness include adverse childhood experiences; history of foster care/child welfare involvement; low education levels; young parenting; chronic health problems; lack of job skills; family breakdown or violence; mental health issues; trauma; substance abuse; and poor social support [9,16]. Secondary disabilities or problems associated with a primary FASD diagnosis have been identified as mental health problems, disrupted school experiences, trouble with the law, incarceration, limited or disrupted education, difficulty finding or maintaining employment, and substance abuse issues [17]. Thus, the secondary disabilities or conditions of FASD mirror many of the factors that place individuals at risk of homelessness and, with the existing primary cognitive disability of FASD, may instigate many challenges to obtaining residential stability.

Understanding and identifying the needs of individuals with FASD who experience homelessness, as well as the extent and nature of FASD within the homeless population, is necessary to determine allocation of resources, funding and effective housing models, and best practices for service delivery. In developing this project, we were concerned about particular vulnerabilities for men and women who have FASD and are homeless including specific concerns such as limited support systems, historical trauma, addictions, mental health problems, and becoming parents. All these factors contribute to the portrait of a complex population with high needs. In order to effectively serve individuals with FASD, a need exists to provide education to frontline workers on specific approaches that can be both supportive and effective. It is anticipated that this research will contribute to a deeper understanding of adults with FASD who experience homelessness and contribute, over time, to the development of a supportive and effective case management model.

The goal of this project is to create awareness of the different service and social support needs of individuals with FASD, as this understanding is foundational in our efforts to end homelessness and to ensure a continuum of care reflective of the different needs of the diverse homeless population. This goal is driven by concerns that we do not have a good understanding of this population in the homeless-serving sector. Participants in this study are referred by case managers or clinicians and have self-reported a diagnosis of FASD to a particular agency during intake and assessment. In cases where no formal diagnosis exists and FASD is suspected, these individuals may also be referred to this study through their case manager. We recognize there are challenges in identification of a population that is somewhat invisible and not subject to universal screening for FASD. A limitation of this study is that we do not have access to diagnostic or medical records as this is not possible. Our intent however, in this research is to identify through multiple sources, the concerns and needs for this population that experience homelessness and to identify gaps within the system. Through this research we can potentially build promising practices for delivering housing and support services to homeless individuals with FASD. Without recognizing the specific care needs and supports for individuals our interventions will not be effective and may, in fact, lead to further negative outcomes. Thus, the purpose of this project is to better understand the concerns and challenges associated with FASD within the single adult episodically and chronically homeless population in order to more effectively address their housing and associated support needs.

MATERIALS AND METHODS

This study was approved by the Conjoint Faculties Research Ethics Board at the University of Calgary on April 23, 2014.

We adopted a mixed methods approach [18] using both qualitative and quantitative components to address the following three questions:

1. What is the prevalence of FASD among the single chronic and episodic homeless population in Calgary (as reported in the Homeless Management Information System [HMIS] CHF database)?
2. How does FASD impact service utilization and client outcomes for people experiencing homelessness?
3. What are the experiences of individuals with FASD in the homeless serving sector?
4. What are promising practices to addressing FASD and supporting individuals with FASD in housing systems?

The mixed method approach for this research study includes the following six components:

- A comprehensive narrative literature review of promising practices for delivering FASD-informed care to people experiencing homelessness, include an analysis of the relationship between FASD, homelessness, and systems involvement;
- An environmental scan of local service providers supporting adults with FASD and support services offered to chronically homeless considered “hard to house”, who may have FASD;
- Quantitative analysis of HMIS data to assess the number of individuals reporting a diagnosis under the spectrum of FASD as well as analysis of system (health, child welfare, and justice) utilization to assess potential cases of FASD;

- Qualitative interviews with 30 chronically homeless adults with diagnosed or suspected FASD, identified by program case managers and/or clinicians and referred to the study;
- Qualitative interviews with 10 service providers to assess housing and support needs for homeless adults with FASD, or suspected FASD, and identify/assess community needs and gaps based on the interview data. Interviews with frontline service providers will also be used to assess the level of awareness and competency in the homeless sector related to FASD, including access to adult diagnostic centres;
- Needs assessment survey regarding the educational and training needs on FASD within the sector.

DISCUSSION

Although research in the area of FASD consistently recognizes that housing is a challenge for individuals with FASD and their families, it rarely identifies homelessness as an issue or explores how to support individuals with FASD into stable housing. As a disability, FASD is seldom recognized by those working in the homeless-serving sector to provide housing and support. This may be due to the “invisibility” of the disability and the difficulty that frontline workers face when dealing with the vast range of disabilities and conditions present in the homeless population with few resources, long wait times for referrals, and continually high staff turnover. Frontline workers also strive to get their clients into housing and to address their immediate and visible needs. This may lead to the oversight of FASD and the misinterpretation of an individual’s behaviors. In Canada, FASD Diagnosis has relied on the Canadian Guidelines for Diagnosis, which were published in 2005 [19] and are currently under revision.

The high social and economic costs of FASD are related to the health of individuals, the impact on community, and the cost of a lifetime of interventions across multiple systems, including unstable housing [20]. Recognizing the needs of individuals with FASD, particularly in relation to health and well-being, is critical in efforts to bring about change in order to more effectively support individuals who have a disability. When FASD goes unrecognized, the risks increase for individuals because supports are often ineffective. From a case management perspective, the need exists for an applied, structured decision making model that is somewhat flexible. The construct of FASD-informed practice has been gaining ground in child welfare practice [21-22]. Another focus of this research is to consider practices and policies that may serve as barriers to individuals experiencing homelessness who live with FASD. It is anticipated that disseminating this research will support those working in the sector to become sensitized to issues and concerns for persons with FASD, leading to a deeper understanding of FASD-informed practice.

CONCLUSION

The aim of this project is to create awareness through gathering information from individuals living with FASD, and those working on the frontlines of ending homelessness. The results from this research will be carefully reviewed with a goal in mind of presenting a symposium of the findings to the CHF and homeless-serving agencies within the region. It is anticipated that recommendations, supported by findings from this research, will be aligned with developing policy and practice recommendations aimed towards advocacy for diagnosis as needed and provision of clinical support for homeless individuals with suspected FASD. It is anticipated that this research will inform the development of strategic decision making regarding resourcing of community supports and housing need for homeless individuals with FASD. Additionally, it is important to bridge gaps between knowledge and the application of promising practices to support and create local and provincial strategies for an FASD informed service delivery for episodic and chronic homeless individuals. Ultimately, the developments of promising practices to support individuals with FASD who experience homelessness are the rationale driving this research. The disadvantages associated with FASD are multiple, and are particularly severe amongst those experiencing homelessness. Thus a goal of this research is to find a beginning place to work with and support a complex population who may be the most vulnerable in the homeless sector.

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