Understanding healthcare access experiences of high users of healthcare with mental health and/or substance use

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Introduction

Over the past 50 years, a significant amount of research has gone into trying to mitigate frequent and high-cost use of health services, increasingly known as “high use of healthcare” (CIHI, 2014). In particular, mental health and/or substance use (MHSU)-related high use of healthcare has continued to be noted as a particularly prominent form of high use of healthcare. Despite this finding, research has not focused specifically on people with MHSU as a distinct group of high users of healthcare and much of this research has not explored perspectives of people with lived experience of high use. Current solutions and treatments for high use of healthcare continue to have inconsistent results. This qualitative interpretive description interview study uses critical participatory action research values to pursue an alternative understanding and possible solutions to high use of healthcare.

Background

Frequently cited statistics around the concept of high use of healthcare allude to the individuals who are high users as the problem. These include statistics like:

- Those above the 95th percentile of cost consume 84% of combined acute and post-acute home care costs
- Those below the 50th percentile of cost distributions account for only 1% of total healthcare costs

The wide use of these statistics reinforce the stigma around high use of healthcare and do little to address the well-documented and significant effect of social determinants of health on health inequity.

Literature Search

A literature search of academic databases using related search terms around MHSU high use of healthcare identified 330 articles. Of these, 148 were relevant to the study and reviewed. Within the 148, only 10 articles were qualitative in nature and explored perspectives of people with lived experience. Few were Canadian and none were from BC.

Key points from the qualitative literature:

- Needs are not being met
- Very negative healthcare experiences
- Demand for trauma-informed care

High use of healthcare in British Columbia

A retrospective cluster analysis study by Moe et al., 2020 found that 58.5% of high use of healthcare cases (top 10% of frequent ED use) fall under MHSU. Despite findings like this, and the fact that British Columbia continues to have the highest number of overdose-related death in the country, there remains a paucity of research examining MHSU high users of healthcare specifically.

“The High Users” Research Team

A peer advisory group was formed consisting of three people with lived experience of MHSU-related experiences of high use of healthcare. These three individuals plus the researcher, a mental health occupational therapist with personal experience with high use of healthcare, make up the “High Users” research team. This is an intentional tongue-in-cheek reference to the current term of choice. The team has worked collaboratively to form study materials and is currently working on recruiting interview participants. The team will also be supporting with thematic analysis of data, and knowledge translation back to the community.

Research Question

What are the perspectives and experiences of high users of healthcare with MHSU around accessing health services in Vancouver, BC?

Objectives:

1. Grow in understanding life contexts of those experiencing MHSU high use of healthcare
2. Identify gaps and get recommendations for better healthcare process
3. Recognize what helps maintain and build resilience for those with MHSU

Methods

- Purposive sampling recruiting adults 18+
- 10-15 in-depth interviews with people with lived experience of MHSU high use of healthcare in the past 12 months
- 2 focus groups with health care providers working with people who are MHSU high users of healthcare
- Thematic analysis of transcripts

References


Limitations

- Not a full-fledged critical participatory action research project
- Small size of participants and research team members
- Difficulty recruiting people in more vulnerable circumstances, compounded by COVID-19

Significance

- Centers those with experiential knowledge of MHSU high use of healthcare as experts and research partners
- Opportunities to bring back findings directly to clinical settings
- First qualitative study exploring MHSU high use of healthcare in BC

The University of British Columbia

This work takes place on the unceded and traditional territory of the Squamish, Musqueam, and Tsleil-Waututh Peoples, to whom we are indebted.