HOARDING BEHAVIOUR AND HOUSING INSECURITY FOR OLDER ADULTS

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ABSTRACT

This research project explores the relationship between hoarding behaviour and housing insecurity among older adults, and provides insights into system-level responses that could reduce housing precarity for seniors with hoarding disorder. The study concludes that addressing hoarding disorder requires a comprehensive, coordinated approach encompassing harm reduction, case management, and systemic changes in service delivery to better support older adults with hoarding behaviours and reduce the economic burden on society. A coordinated, systems-level approach with streamlined referral pathways and standardized reporting systems is proposed to enhance efficiency and efficacy.

RÉSUMÉ

Dans ce projet de recherche, nous explorons la relation entre le comportement d'accumulation compulsive et l'insécurité du logement chez les adultes d'âge mûr. Nous fournissons des éclaircissements sur les mesures systémiques qui pourraient réduire la précarité du logement chez les personnes âgées aux prises avec la syllogomanie. L'étude nous a permis de conclure que le traitement de la syllogomanie nécessite une approche complète et coordonnée. Celle-ci doit englober la réduction des méfaits, la gestion de cas et les changements systémiques dans la prestation de services. L'objectif est de mieux soutenir les adultes d'âge mûr ayant des comportements d'accumulation compulsive et de réduire le fardeau économique sur la société. Afin d'accroître l'efficacité, nous proposons une approche coordonnée et systémique, assortie de procédures d'orientation simplifiées et de systèmes de signalement normalisés.

INTRODUCTION

Hoarding disorder is a mental health issue involving the accumulation of possessions that congest and clutter living areas, and cause significant distress or impairment in social, financial, and other areas of functioning (National Housing Federation, 2015). Individuals living with hoarding disorder experience persistent difficulty in parting with possessions, regardless of their monetary value, due to a perceived need (National Housing Federation 2015). While hoarding behaviour can bear similarities to other mental health disorders and addictive behaviours, it has been classified as its own mental disorder since 2013: this relatively recent classification means that it is severely understudied, even though 2-5% of the general population is thought to be living with hoarding behaviour - twice the rate of obsessive compulsive disorder, and four times the rate of schizophrenia and bipolar disorders (Samuels et al. 2008).

Although hoarding primarily manifests itself within the home, and housing associations are often the first line of engagement for individuals with hoarding disorder, there is little research exploring the impact of hoarding behaviour on housing security (National Housing Federation 2015). Hoarding behaviour is also up to three times more prevalent in older adults than in younger populations, and is likely inversely related to household income (Samuels et al. 2008). This report seeks to address a gap in housing research by exploring the relationship between hoarding behaviour and housing insecurity for older adults.

Through the Hoarding Behaviour and Housing Insecurity for Older Adults project, we explored the relationship between effective responses to hoarding and housing insecurity, so that we might provide insight into a systems-level response that leads to a reduction in precarity for seniors with this disorder. Specifically, the study focused on 1) the scope and nature of the relationship (i.e. extent and quality of the correlation) between hoarding behaviour and housing insecurity for older adults, and 2) the interventions employed by community-based organizations, municipalities, and housing agencies to increase the housing security of older adults living with hoarding behaviour. Research focused on three key questions:

1. What proportion of older adults who have been identified as living with hoarding behaviour are experiencing housing insecurity?
2. In what ways does hoarding behaviour impact housing insecurity for these older adults?
3. What types of interventions are most effective in increasing housing security for older adults living with hoarding behaviour?

The study involved a phased approach: an environmental scan and literature review were conducted to establish the scope of the issue, identify the number and type of programs addressing hoarding behaviour across Canada, and provide a conceptual grounding for further study; and a targeted survey and interviews with frontline practitioners were used to explore

the nature of the relationship between hoarding behaviour and housing insecurity, and provide insight into effective service responses.

TERMINOLOGY

Several of the terms used in this report can signify in different ways, and warrant addressing or explanation. For example, the word 'senior' can refer to anyone over the age of 50, but can also have a legal or systemic designation (e.g. aged 65+) when accessing housing, income supports, and other social supports. For that reason, a brief explanation of key terms used in this report is provided below.

SENIOR AND OLDER ADULT

Ageism[1] is a key barrier to participation for seniors that can significantly impact quality of life. It can lead to the isolation, invisibility, and social exclusion of older adults. It can also be a cause for individual acts of age discrimination and can lead to elder abuse. It can have a negative impact on the mental and physical health of older adults and increase their vulnerability. A further challenge with ageism is that people of all ages can hold ageist beliefs, including seniors themselves. This internalized ageism can be a critical barrier to access: when older adults reject the idea that they are 'seniors', they may be less likely to access the resources, support, and opportunities available to them because of their age.

Ageism is a way of thinking and making assumptions about older people based on negative attitudes and stereotypes about aging, and that can include the language that we use. For this reason, we use the words 'senior' and 'older adult' interchangeably in this report. For the purposes of our survey and interviews, participants were asked to consider their work with people over the age of 55.

HOMELESSNESS AND HOUSING INSECURITY

Homelessness is the generally accepted term for someone who does not have "stable, safe, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it" (Gaetz et al., 2012). The Canadian Observatory on Homelessness describes a spectrum of homelessness with 'unsheltered' on one extreme and 'at risk of homelessness' on the other. The spectrum includes anyone living on the street or an equivalent, people staying in emergency and domestic violence shelters, people living in temporary or insecure housing, and

[1] The term ageism refers to two separate but connected ideas. It is both 1) a way of thinking and making assumptions about older people based on negative attitudes and stereotypes about aging, and 2) a tendency to structure society based on the assumption that everyone is 'young' and failing to consider the needs of older people.

those whose housing is unsafe or precarious. Within the 'at risk of homelessness' category, the Canadian Definition of Homelessness (Gaetz et al., 2012) delineates between people who are precariously housed and those who are at imminent risk of homelessness: the latter are defined as those who are precariously housed when they experience a crisis or escalation of a significant risk factor (e.g. sudden unemployment). The terms 'precariously housed' and 'experiencing housing insecurity' are used in this report to refer to people who are experiencing challenges that could lead to homelessness, including but not limited to the effects of hoarding behaviour.

It is worth noting that the Canadian Observatory on Homelessness identifies the opposite of 'homelessness' as housing stability, which is defined as "a fixed address and housing that is appropriate (affordable, safe, adequately maintained, accessible and suitable in size), and includes required income, services and supports to enhance their well-being and reduce the risk that they will ever become homeless" (Gaetz et al., 2012). Given this definition (whereby the opposite of homelessness is housing stability), the growing awareness of the ways in which the term 'homeless' decentres the individual from the situation they are experiencing, and the potential to experience a sense of 'home' beyond the physical plant of a building, the terms 'houseless' and 'houselessness' are used where possible in this report instead of the terms 'homeless' and 'homelessness'.

HOARDING BEHAVIOUR AND HOARDING DISORDER

Prior to being classified as a disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, hoarding was considered a symptom of obsessive compulsive disorder (OCD). Its designation as a separate disorder is in part because an individual's hoarding-related thoughts are not perceived as invasive or unwanted, as they would be in the case of OCD: importantly, for people living with hoarding disorder, "distress is usually as a result of a third party's interference, such as relatives or the authorities, and as a result of the thought or action of removing the item rather than the acquisition" (SAMHSA, 2016, p. 137). Criteria for the diagnosis are indicated in Table I.

Clients accessing supports related to the impacts of their hoarding behaviour may or may not have a clinical diagnosis. For the purposes of this report, the term 'hoarding disorder' is used generally to describe a state of struggle with the effects of hoarding behaviour, and does not presume a clinical diagnosis.

TABLE I
DSM-5: HOARDING DISORDER

Disorder Class: Obsessive-Compulsive and Related Disorders
Persistent difficulty discarding or parting with possessions, regardless of their actual value.
This difficulty is due to a perceived need to save the items and to the distress associated with discarding them.
The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities).
The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment safe for oneself or others).
The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive defects in major neurocognitive disorder, restricted interests in autism spectrum disorder).
Specify if: With excessive acquisition: If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space. (Approximately 80 to 90 percent of individuals with hoarding disorder display this trait.)
Specify if: With good or fair insight: The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic. With poor insight: The individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary. With absent insight/delusional beliefs: The individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.

Source: Substance Abuse and Mental Health Services Administration (June 2016).

CONTEXT

Sage Seniors Association (Sage) is a multi-service senior-serving organization providing a wide range of programs and services to seniors in the greater Edmonton area. We employ a strengths-based approach that seeks to increase resilience and reduce vulnerability in seniors when needed, and to inspire them to keep engaging with, building, and enriching our communities.

Over time, Sage has become recognized as having expertise and programming that specifically addresses the needs of seniors with complex needs. We have adopted the term 'low-resourced', as it clearly articulates in non-oppressive terms the individuals that Sage typically serves. Low-resourced seniors are those experiencing marginalization or are hard to reach, such as those who are: houseless or housing insecure; living with a physical or mental disability; newcomers or English language learners; providing caregiving; lacking access to family and social supports; living with a low income or financially challenged with limited disposable income, and have limited access to financial resources. Many seniors experience barriers to accessing programs and services, and these issues are more pronounced for those with low resources. Sage works to help seniors overcome those barriers.

Since 2007, part of our service provision has included This Full House, a program providing support to individuals aged 55+ who struggle with compulsive hoarding behaviour. Through the program, staff undertake assessments and work with seniors to set goals, establish timelines, facilitate connections to information and resources, and facilitate support groups.

In 2013, Sage Seniors Association released a report proposing an integrated community response to hoarding that involved a comprehensive case management approach with a program manager, central intake line, standardized referral and assessment tools, a services roadmap and public education plan, and an inter-agency coalition (Sage Seniors Association, 2013). The report concluded that coordination of services would increase access, improve system-level efficiencies and decrease the burden of complex cases on individual organizations, and called for dedicated funding to sustain an integrated response to hoarding over time.

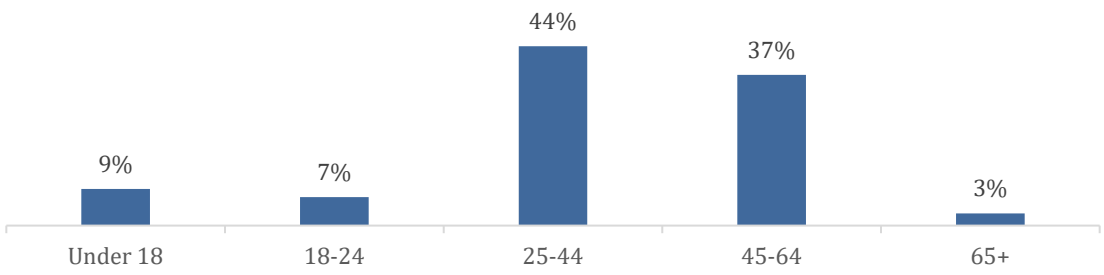
Sage also co-founded the Edmonton Hoarding Coalition, a collaborative network of community organizations, housing providers, government agencies, and for-profit business with the goal of providing an integrated service response to hoarding cases. Coalition members include the city's largest affordable housing provider for seniors (Greater Edmonton Foundation Seniors Housing), Alberta Health Services (Environmental Health and Home Care), Edmonton Bylaw, Edmonton Fire Rescue, and community-based organizations addressing housing insecurity and homelessness, such Homeward Trust. These organizations work together with limited resources to support people struggling with hoarding disorder and keep them safely housed. However, demand for hoarding support among older adults and others continues to exceed capacity, and

despite the recommendation made by Sage's 2013 report, there is still not permanent funding for hoarding-related programs in Edmonton.

Hoarding disorder is a progressive, chronic illness with complex contributing factors. People with hoarding disorder are more likely to have multiple coexisting conditions and have significantly higher rates of service use: because physical limitations and cognitive decline may occur with aging, older adult hoarding cases can become extremely complex.

Houselessness in seniors is also growing. Older adults comprise a growing proportion of people experiencing houselessness, and are the only demographic whose shelter use continues to increase (Gaetz et al., 2016): in 2018, 40% of people who were identified as being houseless in Alberta were aged 45+ (see Figure I). There are increasingly limited options for appropriate, affordable housing for younger seniors (aged 55-64), and low-income seniors in this age group are at greater risk of housing, financial, and food insecurity as a growing proportion of their income is allocated to rent.

FIGURE I
2018 Alberta Point-in-Time homeless Count
Government of Canada (June 2018)



With this report, we are building on the work first completed in 2013, by exploring the relationship between hoarding disorder and housing insecurity, to better understand how system-level changes could be made to improve outcomes for this extremely vulnerable population. This report explores the impact of hoarding disorder on individuals and communities, the importance of adopting a harm reduction and case management approach, and the need for systematic changes in service delivery to address the effects of a complex issue that not only impacts the individual but poses environmental and health risks for others, and places a significant economic burden on community-based organizations, housing providers, and emergency services (Hanson and Porter, 2021).

METHODOLOGY

This research project involved two phases of data collection and analysis: in Phase I, we established the scope of the issue, developed a conceptual grounding for the study, and

explored existing hoarding responses through an environmental scan, literature review, and targeted survey. Phase II involved interviews with frontline practitioners and other professionals with expertise in hoarding disorder.

RESEARCH QUESTIONS

Q1 What proportion of older adults who have been identified as living with hoarding behaviour are experiencing housing insecurity?

Q2 In what ways does hoarding behaviour impact housing insecurity for these older adults?

Q3 What types of interventions are most effective in increasing housing security for older adults living with hoarding behaviour?

A targeted survey was disseminated to organizations within the Edmonton Hoarding Coalition's professional network and other organizations identified by the environmental scan (convenience sampling), with the goal of gathering data to answer Q1 and Q2 (see sidebar). The survey was primarily comprised of multiple choice questions and ratio scales, to allow for comparison without requiring individual-level data. A literature review focused on integrated service responses to hoarding and housing insecurity, and a series of semi-structured interviews with representatives from agencies engaged in robust hoarding support networks was used to answer Q3.

Sage employs a trauma-informed approach in all of our work, including any research we undertake. As a result, we relied on anonymous, aggregate data from participating organizations, and leveraged the knowledge and experience of the front-line staff who have developed a deep understanding of the issues through their daily practice, including service provision, system navigation, and advocacy. By focusing our primary data collection on service providers rather than seniors with lived experience, we sought to prevent traumatizing or interfering with the support of seniors struggling with hoarding behaviours and facing housing insecurity. Because the project seeks to identify and understand system-level issues, engaging with service providers and practitioners was the most effective and appropriate approach for this project.

ENVIRONMENTAL SCAN

An environmental scan of hoarding-related programs offered nationwide was conducted by the Edmonton Social Planning Council on behalf of Sage Seniors Association. A search for programs and/or organizations lead by people with lived and/or living experience of hoarding disorder was also included. The scan was primarily conducted via Google and provincial databases.

Results from the scan include community-based and for-profit organizations that offer counselling, support, and outreach programs; cleaning, decluttering, and organizing services; and hoarding-related support groups, coalitions, and collaborations. A summary list of community-based programs and coalitions explicitly addressing hoarding behaviour is provided in Appendix I.

LITERATURE REVIEW

The literature review created a conceptual base for the interviews by identifying the conditions that result in housing precarity, the types of service responses that are carried out in hoarding cases, and what it means for a service response to be effective in increasing housing security for seniors struggling with hoarding behaviour.

Information gathered through a review of academic and grey literature was collated and organised into broad themes (see Table II). While most research did not focus on low-resourced seniors or housing insecurity, these issues were nonetheless evident because:

1. hoarding behaviours generally manifest during younger years and worsen overtime - as a result, participants typically fell within the age range of interest for this research project (55+), and;
2. people with hoarding behaviours tend to experience other vulnerabilities such as unemployment, poverty, houselessness, and housing insecurity.

Therefore, the literature review provided a sufficient basis for the development of the engagement materials for this research.

TABLE II
LITERATURE REVIEW: THEMES

Defining Hoarding Disorder	Implications of Hoarding Behaviour for Older Adults	Interventions and Case Management	Poverty, Houselessness, and Housing Insecurity
Profile of People with Hoarding Behaviours	Employment Outcomes	Harm Reduction	Impact of Hoarding Behaviour on Landlords
Prevalence of Hoarding Disorder	Comorbidities and Additional Vulnerabilities	Interdisciplinary Approaches	
		Issues in Service Delivery	

Insight into the types of interventions that most effectively increase housing security for older adults living with hoarding behaviour (Q3) was generally derived from the policy and/or organisational implications of the research that we found. In particular, we were interested in how clients and service providers interface with the system (e.g. challenges, ease, procedures, best practices) and found that the literature emphasised collaborative and interdisciplinary approaches to case management.

A research gap in the post-intervention analysis of housing security for clients with hoarding behaviours was identified. Existing research focuses primarily on how interventions successfully manage or improve the symptoms of hoarding disorder: with this project, we focus on the relationship between hoarding interventions and housing insecurity.

TARGETED SURVEY

A 15 question survey (see Appendix II) was developed to collect aggregate-level data on how hoarding behaviour is correlated with housing insecurity and other precarious situations such as houselessness and poverty. Survey questions were organized into three sections: organization (e.g. field, programs, staff); client (e.g. population served; % struggling with hoarding behaviour); and housing insecurity (e.g. % of hoarding-related clients experiencing housing insecurity).

The survey was disseminated to Edmonton Hoarding Coalition (EHC) members on December 15, 2022, and closed on January 6, 2023. Eleven people responded to the survey, representing organizations working in healthcare, mental health, housing, fire, and social services. One person with lived/living experience, who is a member of the EHC, also responded. An initial analysis of the survey data indicated that the survey sample might be too small to provide sufficient insight into the research questions or direct further inquiry, and identified a need to broaden the reach of the survey beyond Coalition members.

The environmental scan had identified 46 organizations or coalitions across Canada that are working with people struggling with hoarding behaviour. From this, 19 organizations were flagged as a potential match for the research study (survey and/or interview). These organizations were contacted by email or phone as appropriate, and as a result of these efforts, we received five additional survey responses (including two from outside Alberta) and secured two further interview candidates (both in Alberta). New survey respondents represented organizations working in the fields of seniors health, bylaw, law, and mental health. An overview of all respondent organizations is provided on pages 12-13.

INTERVIEWS

Semi-structured interviews were conducted via Zoom between May and July 2023 (see Appendix III). Six participants from three geographic areas (Edmonton, Calgary, Lethbridge) were interviewed, including a social work manager (1), public health inspector (1), lawyer (1), case manager (1), executive director (1), and program instructor (1). Interviews were recorded and transcribed, and a qualitative thematic analysis was applied to identify salient themes and uncover other patterns (or absence of patterns). Interview content was coded, clustered, and themed: themes were analyzed within the context of each question and a summary analysis for each question was developed.

OVERVIEW OF SURVEY RESPONDENTS

CHART I

Q2: Which programs or services does your organization offer? (select all that apply)

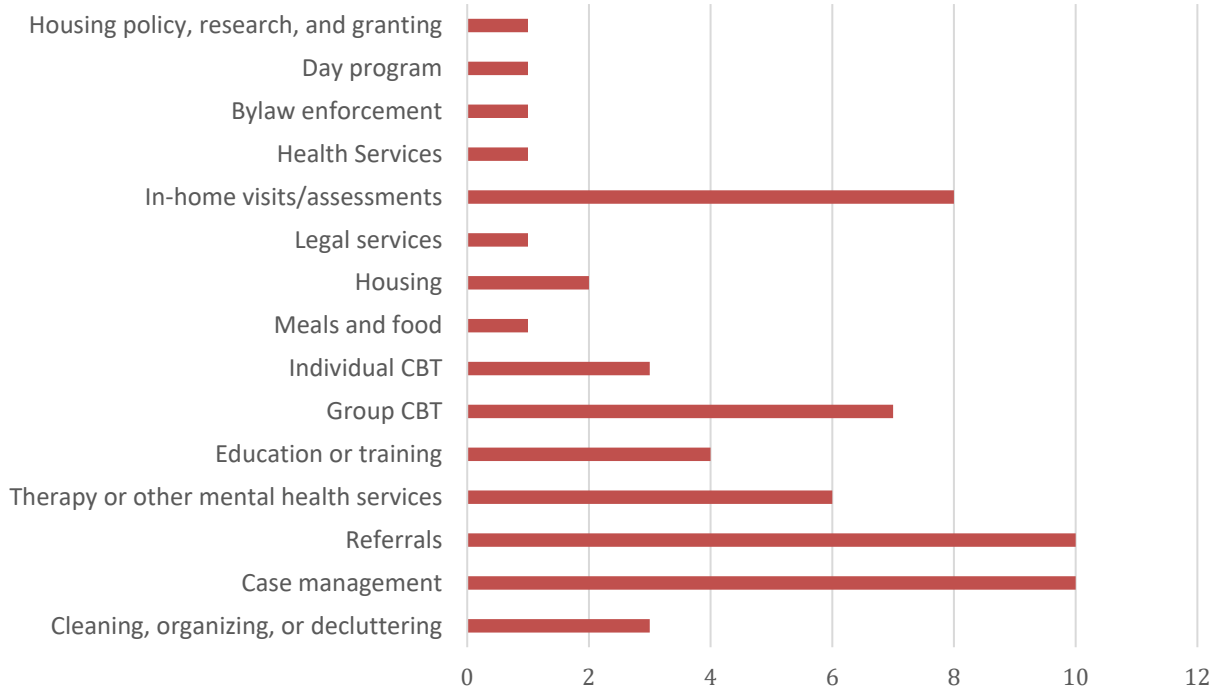


CHART II

Q3: In the context of hoarding, which area does your organization primarily operate?

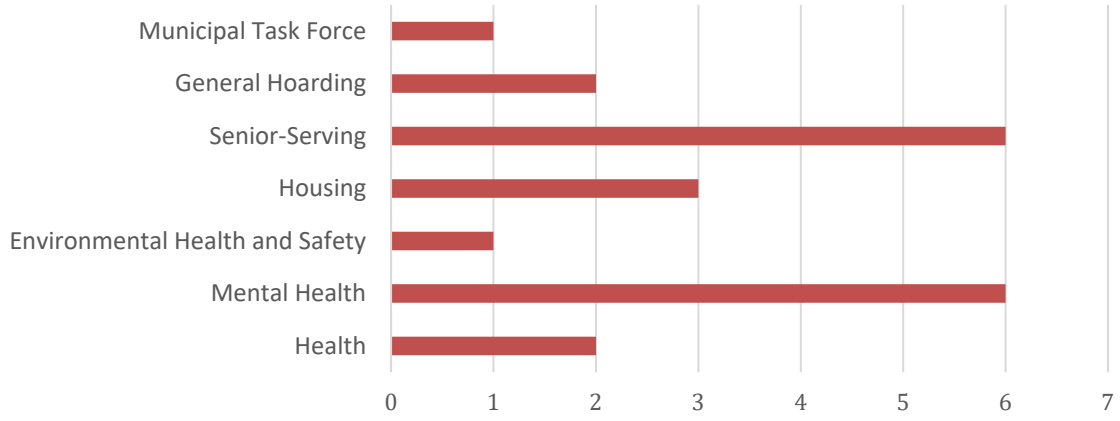


CHART III

Q4: Does your organization have staff with the following designations? (select all that apply)

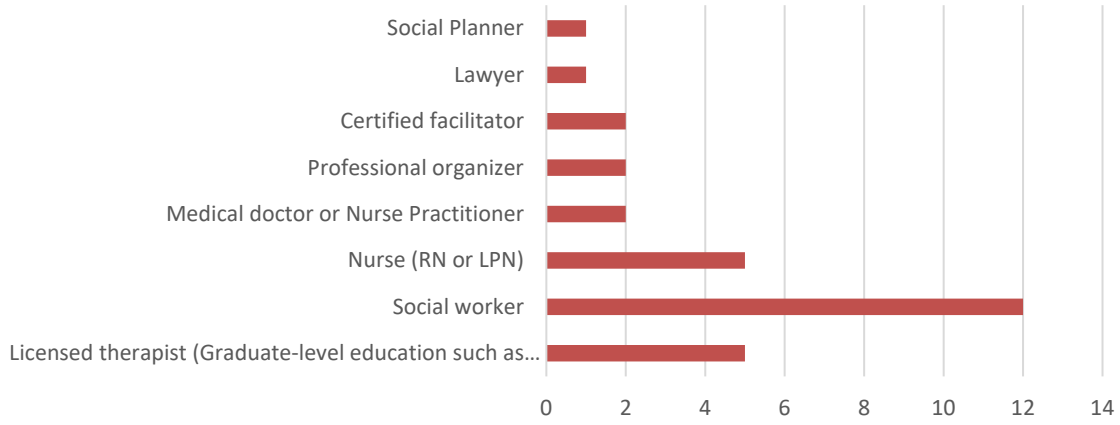


CHART IV

Q5: Approximately how many people aged 55+ (with or without hoarding behaviour) does your organization serve a year?

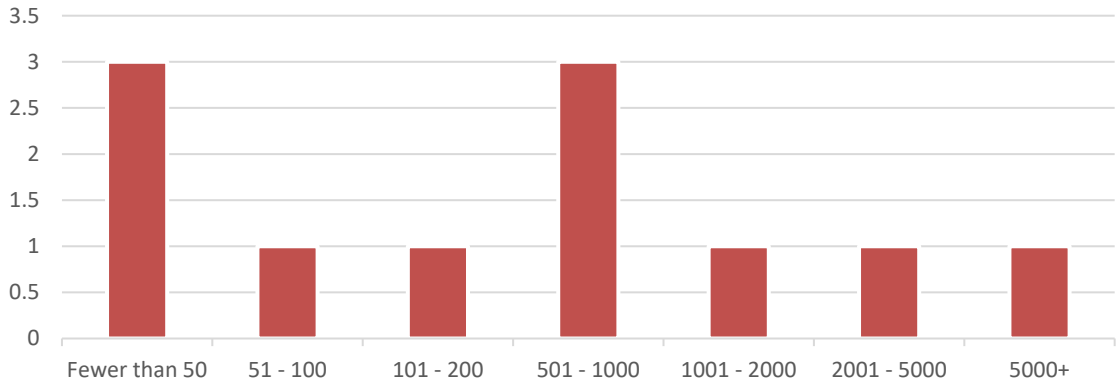
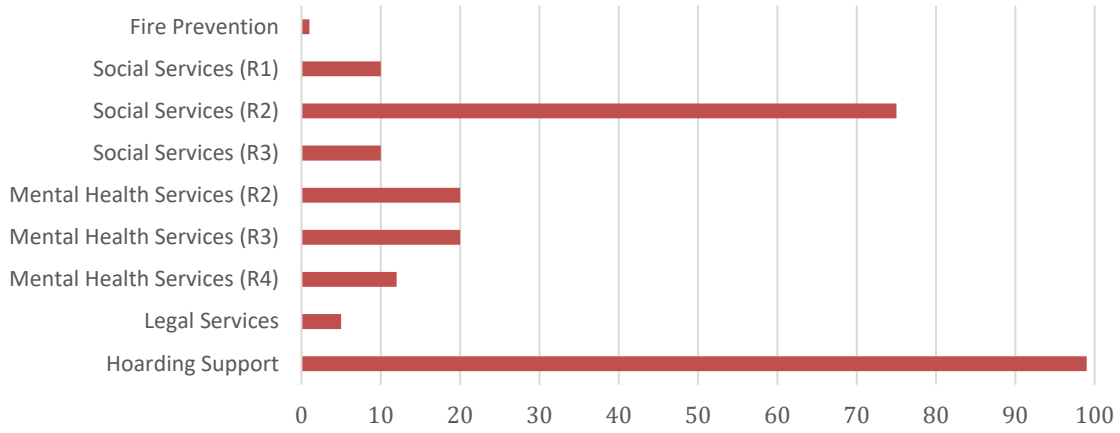


CHART V

Q6: Approximately what % of people aged 55+ that you serve exhibit hoarding behaviour?



LITERATURE REVIEW

HOARDING BEHAVIOUR AND HOUSING SECURITY

Hoarding disorder is a public health issue that not only affects people with hoarding behaviours but their families, friends, neighbours, communities, and animals as well. Hoarding behaviours result in a series of interrelated and reinforcing negative outcomes on a person's wellbeing, and reduce quality of life by causing distress and reduced function across different aspects of daily living. People struggling with hoarding behaviour use healthcare services more often, and have a higher propensity to experience chronic medical impairments, mental health issues, and housing insecurity (Government of Western Australia, 2013; Hanson and Porter, 2021).

Hoarding behaviours significantly impact the mental and emotional wellbeing of people with hoarding disorder, who may be isolated from their social networks, and can lead to feelings of exclusion and marginalisation. These behaviours also affect family members, who often experience marginalisation or isolation, have impaired relationships, lower rates of marriage, higher rates of divorce, loss of normal family life, reduced living space and social life, and negative feelings toward the person with hoarding disorder. Family members often misunderstand, are confused or in denial of the condition, and this can result in more frequent conflicts (Sehn et al., 2020).

Existing research indicates a strong link between hoarding disorder and housing insecurity, and notes that securing a client's tenancy is among the foundations of supporting people with hoarding disorder (Bratiotis, Woody, and Lauster, 2018). Clutter and hoarding are more common among low-income and marginalised households, and hoarding behaviour is a primary reason for marginalised populations to have unsafe housing conditions (Lemieux et al., 2018): demographically, this group tend to be older adults with health issues, who are living alone.

People with hoarding disorder may live in unsafe and unsanitary homes that have environmental and health risks, including combustion hazards (malfunctioning appliances and exposed wiring), and blocked exits: these hazards make it difficult for first responders seeking entry to the home for emergencies, which may increase fatalities (Bratiotis, Woody, & Lauster, 2018). For example, a study in Melbourne, Australia (Lucini, Monk, & Szlatenyi, 2009) found that 24% of all preventable fire fatalities over a ten-year period occurred in hoarded homes, even though hoarding-related incidents represented only 0.25% of residential fires overall.

Hoarding behaviour is especially dangerous in high-density areas or buildings, where the effects of excessive clutter increase housing risks to all residents (Lauster et al., 2016; Bratiotis, Woody, and Lauster, 2018). One study (Lauster et al., 2016) found that while 5-5.6% of residential units in Vancouver were identified as being problematically cluttered according to official inspections, inspectors would often fail to provide written notice of the concern to housing providers because they feared the tenants would be evicted. The study also found that

nonprofit housing providers are less likely to evict tenants than private residential managers, to prevent people from becoming houseless. The lack of intervention results in continued accumulation that can become increasingly risky and hazardous for other residents, which increases their housing insecurity as well.

The physical space occupied by low-resourced households tends to be smaller, and these residents may accumulate possessions at a rate that is more problematic relative to the size of their properties (Lauster et al., 2016). For example, the San Francisco Task Force on Compulsive Hoarding (2009) interviewed one housing provider serving low-income populations who indicated that 10% of their 1,800 units had tenants with significant hoarding behaviours and an additional 30% had potentially problematic hoarding behaviours. Lauster et al. (2016) found that 7% (1 in 14) of living units in single-room occupancy hotels in Vancouver, BC (geared towards low-income individuals or those at-risk of houselessness) had hazardous or problematic levels of clutter, which is higher than published studies estimating a 2-5.8% prevalence of hoarding disorder overall. The same study estimates that if everyone in single-room-occupancy hotels living with problematically cluttered units were evicted, Vancouver's houseless population would increase by 20% (relative to the 2011 point-in-time count).

Experiencing or being at risk of houselessness is a persistent issue faced by people with hoarding behaviours. In one study, the San Francisco Task Force on Compulsive Hoarding (2009) found that 61% of survey respondents (service providers) indicated that their clientele was houseless. In New York City, a study by Rodriguez et al. (2013) found that 22% of clients screened for hoarding disorder at the Eviction Intervention Services Housing Research Centre were clinically rated to have hoarding disorder: approximately a third of those clients were facing imminent eviction, 44% had been previously threatened with eviction, and 20% had been evicted at least once. Similarly, a study by Mataix-Cols et al. (n.d.) found that of 78 randomly selected houseless people admitted to a Salvation Army in the UK, 21% showed signs of hoarding disorder and 8% reported that hoarding contributed to their becoming houseless (Millen et al., 2020). In another study, Greig, Tolin, and Tsai (2020) used the Clutter Image Rating scale to determine that 18.5% of people in supportive housing displayed hoarding behaviours. An American study (Tolin et al., 2008) found that 37.9% of participants with compulsive hoarding behaviour were living in poverty and 7.8% of participants had been threatened with eviction or were evicted.

Other consequences intensify the precarious situations faced by people with untreated hoarding disorder. Hoarding behaviours can lead to tension with neighbours and property managers that may result in eviction and houselessness. Legal issues and attempts to manage hoarding behaviour also place significant financial pressure on people experiencing the disorder and impact their employment, which leads to increased housing insecurity and a greater

probability that they will experience social exclusion, and poor mental and physical health (Government of Western Australia, 2013).

The situations caused by hoarding disorder are further stressors that can reinforce the hoarding behaviour itself, and result in sustained or exacerbated states of precarity. For example, the San Francisco Task Force on Compulsive Hoarding (2009) found that people struggling with hoarding behaviour had more difficulty maintaining a job, lost more days of work, and were less productive than others. Toli et al. (2018) found that study participants with compulsive hoarding behaviours averaged seven work impairment days in the preceding month. Sehn et al. (2020) also found that people with hoarding disorder missed a greater number of workdays, had difficulties with performing daily activities and self-care, and caused difficulties for emergency service responses (e.g. hard to manoeuvre in the space).

People struggling with hoarding behaviour also experience physical and mental health issues or comorbidities that affect their ability to seek support and succeed in interventions. Tolin et al. (2008) found that study participants and their family members were approximately three times more likely to be overweight or obese. Participants with compulsive hoarding also had higher self-reported rates of chronic conditions and used mental-health services five times more than the general population. A study conducted by Porter and Hanson in England (2022) found that out of 38 participants experiencing hoarding behaviour, 47% had a known disability or vulnerability (defined as self-reported additional mental and physical needs) and 34% lived with a fire risk. Interviews conducted by Hanson and Porter (2021) found that nearly half of people with hoarding disorder in Norwich, England, had a known disability and lived alone in apartments, which presented a risk to other people living in the same building.

Older adults and seniors are particularly vulnerable to the housing insecurity caused by hoarding disorder, and hoarding behaviour is increasingly a reason for eviction for this population (San Francisco Task Force on Compulsive Hoarding, 2009; Zell and McCullough, 2021). Hoarding behaviours manifest during younger years and continue to worsen over time: people with hoarding disorder may not be identified or diagnosed until the condition has advanced significantly, which makes subsequent interventions more difficult (Dozier, Porter, and Ayers, 2016). The compounding effects of housing and employment insecurity, comorbidities, and increased isolation can make it extremely difficult for people to seek information or support for their condition, and this can be exacerbated by the judgement and stigma surrounding hoarding disorder (Porter and Hanson, 2022). Interviews from the Hanson and Porter (2021) study also revealed that frontline staff dealing with people with hoarding disorders had deficiencies in trauma-informed practices and finding adequate long-term solutions for their clients. Frontline staff were typically not well-versed or trained in dealing with mental-health issues, which was generally beyond the scope of their roles.

INTERVENTIONS AND CASE MANAGEMENT

The State of Victoria, Australia Department of Health (2013) recommends early intervention for hoarding disorder to avoid addressing the issue when it is more difficult to treat, as symptoms worsen over time. Research conducted by the San Francisco Task Force on Compulsive Hoarding (2009) found that the most common services used or desired by people struggling with hoarding behaviours include support groups, therapy, professional organisers, in-home support services, and 'clutter buddies' to help manage symptoms and expand social networks. The taskforce also found that people with hoarding behaviours valued legal services, training, and education to help prevent eviction and houselessness.

Because people typically exhibit hoarding behaviour far earlier than when they are diagnosed, older adults and seniors with hoarding disorder require support not just for their hoarding behaviour, but the long-term impact it has had on their physical, mental, social, and financial wellbeing as well. Whitfield et al. (2011) found that cognitive behavioural therapy (CBT) is an effective treatment for hoarding disorder, because it allows clients to understand and share their experiences with peers, and gain insight to the causes of their condition. The use of CBT to treat hoarding disorder was pioneered by Frost and Hartl (1996) and has been frequently used by service providers thereafter. This approach develops problem solving skills, trains the client in new behaviours and beliefs about hoarding, and gives them the tools and resources they need to discard and declutter (Weir, 2020; Rodger, McDonald, & Wootton, 2021). Many older seniors have also experienced loneliness and isolation as a result of their hoarding, which can be exacerbated by feelings of guilt and shame, and Whitfield et al. (2011) found that sharing common experiences with their peers in group CBT programs increases the sense of belonging among older adults with hoarding disorder, and can have a positive impact on the progression of their condition. Turner, Steketee, and Nauth (2010) recommend that service providers invest in obtaining CBT training or certification to increase the effectiveness of their program delivery.

Weir (2020) cautions that CBT may be less effective among older clients, because they may be more invested in their status quo and resistant to behavioural interventions. However, Turner, Steketee, and Nauth (2010) found that CBT reduced the severity of hoarding among participants aged 56+ who completed their pilot study. Study participants faced several challenges and other conditions, and the authors found that the problem-solving skills taught in CBT were particularly beneficial to them. Another study (Sehn et al., 2020) found that group CBT can help reduce isolation and feelings of shame and guilt; increase social interaction among peers; increase trust, engagement, and motivation; and increase the likelihood that participants will complete assignments at home. Mathews et al., (2018) found that peer-led interventions were also effective in reducing hoarding severity.

A 2009 study in San Diego, California (Ayers et al.) found that social impairment and diminished social networks were common characteristics among their participants (aged 60+). Participants

were mostly living alone, were retired, and divorced, or had never married**.** Many participants were also struggling with mood or anxiety disorders, had obsessive compulsive disorder (OCD) or experienced major depression, and had received psychiatric care at some point. Most participants indicated that they had never received behavioural therapy for hoarding.

Case management approaches are commonly applied to social services provision, including programs addressing hoarding behaviour. A key consideration for the case management of seniors struggling with hoarding behaviour is securing their tenancy and helping them to age in place (Whitfield et al., 2011; Frank & Misiaszek, 2012), which often includes in-home assistance with the activities of daily living (ADLs): for example, seniors may need help with organising, cleaning, and sorting. In-home assessments can also include support with housing infractions threatening tenancy, health and safety risks, and lease/code violations (Bratiotis, Woody, and Lauster, 2018). Rodger, McDonald, and Wootton (2021) note that in-home assistance is a critical success factor, with those receiving in-home visits having better outcomes than those who do not receive visits.

There is no cure for hoarding disorder: instead, interventions and treatments need to help people adopt healthier hoarding-related behaviours and manage correlated conditions. Case management in this area has evolved in recent years to focus more on client-empowerment (Bratiotis, Woody, and Lauster, 2018), which allows clients to access supports while retaining control over decisions (Whitfield et al., 2011). Some interventions and supports for people struggling with hoarding disorder are ineffective, counterproductive, or harmful: these include one-off clean-ups initiated and undertaken by third parties, and not acknowledging that hoarding is a mental health concern (Frank and Misiaszek, 2012; State of Victoria, Department of Health, 2013).

The multifaceted challenges faced by individuals with hoarding behaviour extend beyond their immediate living conditions, affecting relationships, safety, and general well-being. The San Francisco Task Force on Compulsive Hoarding (2009) revealed that individuals with hoarding behaviour experience isolation, strained relationships, safety concerns at home, and constant fear of eviction. The consequences often lead to family tension and estrangement, and can significantly impact mental and emotional health. Porter and Hanson (2022) emphasize the importance of a harm reduction and case management approach when addressing hoarding behaviour, citing Vancouver's successful implementation of the Hoarding Action Response Team (HART) using this model.

Effective interventions for hoarding disorder must ensure that the clients' situations and symptoms are not exacerbated, and should empower clients through strengths-based and person-centred approaches (Bratiotis, Woody, and Lauster, 2018). For this reason, harm reduction strategies are generally employed by professionals addressing the effects of hoarding

disorder. Harm reduction leverages an individual's skills and abilities toward making incremental changes and managing their symptoms (Whitfield et al., 2011), and focuses on increasing the client's safety, and protecting their dignity. Gibson (2015) however, notes that harm reduction has limitations. Health and safety risks need to be addressed in a timely manner to ensure that an individual does not cause harm to themselves and others. A harm reduction approach may also fail to address the root causes of the hoarding behaviour, and the client may find their clutter and hoarding worsening again over time. As a result, Gibson (2015) argues that a harm reduction approach should be used as a starting point that underpins further treatment.

Bratiotis, Woody & Lauster (2018) found that setting achievable, client-centred goals that leverage the strengths of the client can help address the unique needs and experiences of the individual. When clients are not able to set and work toward small, incremental goals, crisis intervention becomes necessary. Harm reduction in these instances include reducing fire risks (e.g. moving combustibles away from heat sources), throwing away unsafe food, and clearing pathways.

A supportive and knowledgeable support system is also important in managing hoarding symptoms among older adults and seniors. Diminished or unavailable support networks can hinder a client's ability to seek help and manage their symptoms, and interventions should help facilitate greater involvement from their natural supports. This can mean helping a client's support system to be non-judgemental and active in promoting their independence, dignity, and wellbeing (Bratiotis, Woody, and Lauster, 2018; Hanson and Porter, 2021).

AN INTERDISCIPLINARY APPROACH TO CASE MANAGEMENT

The complexities of case management for older adults struggling with hoarding behaviour have led to growing support in the literature for service coordination and interdisciplinary approaches to service provision. An interdisciplinary approach to addressing hoarding disorder links together professionals from different fields, enables greater collaboration and streamlining of services, and facilitates the development of wraparound services (Bratiotis, Woody & Lauster, 2018). The benefits to coordinated and integrated responses to hoarding include leveraging limited resources among agencies and facilitating information/knowledge transfer to improve understanding of client needs. Integrated approaches to case management foster a holistic approach to service provision and support proactive and timely solutions to complex concerns. Increasing the expertise and capacity of frontline staff across organizations can also reduce the stress and pressure of emotionally and physically taxing roles (Hanson and Porter, 2021) as different stakeholders build on each other's efforts and remove inefficiencies.

Interdisciplinary teams draw on the expertise of different fields (e.g. health providers, animal control, law enforcement, mental health) to help clients manage their unique circumstances at each point in their treatment, increase the effectiveness of hoarding interventions (Porter and

Hanson, 2022), and improve outcomes for clients with hoarding disorder (Bratiotis, Woody & Lauster, 2018). Coordinated and integrated responses include the creation of task forces, intersectoral approaches to bridging service gaps, and building multidisciplinary teams from public and private organisations (Sehn et al, 2020). Whitfield et al. (2011) note that collaboration among service providers leverages the expertise and skills of different professionals, and enhances each participant's own expertise on hoarding behaviour. Bratiotis, Woody & Lauster (2018) found that training and education provided to the community and service providers were useful in brokering relationships and coordinating services.

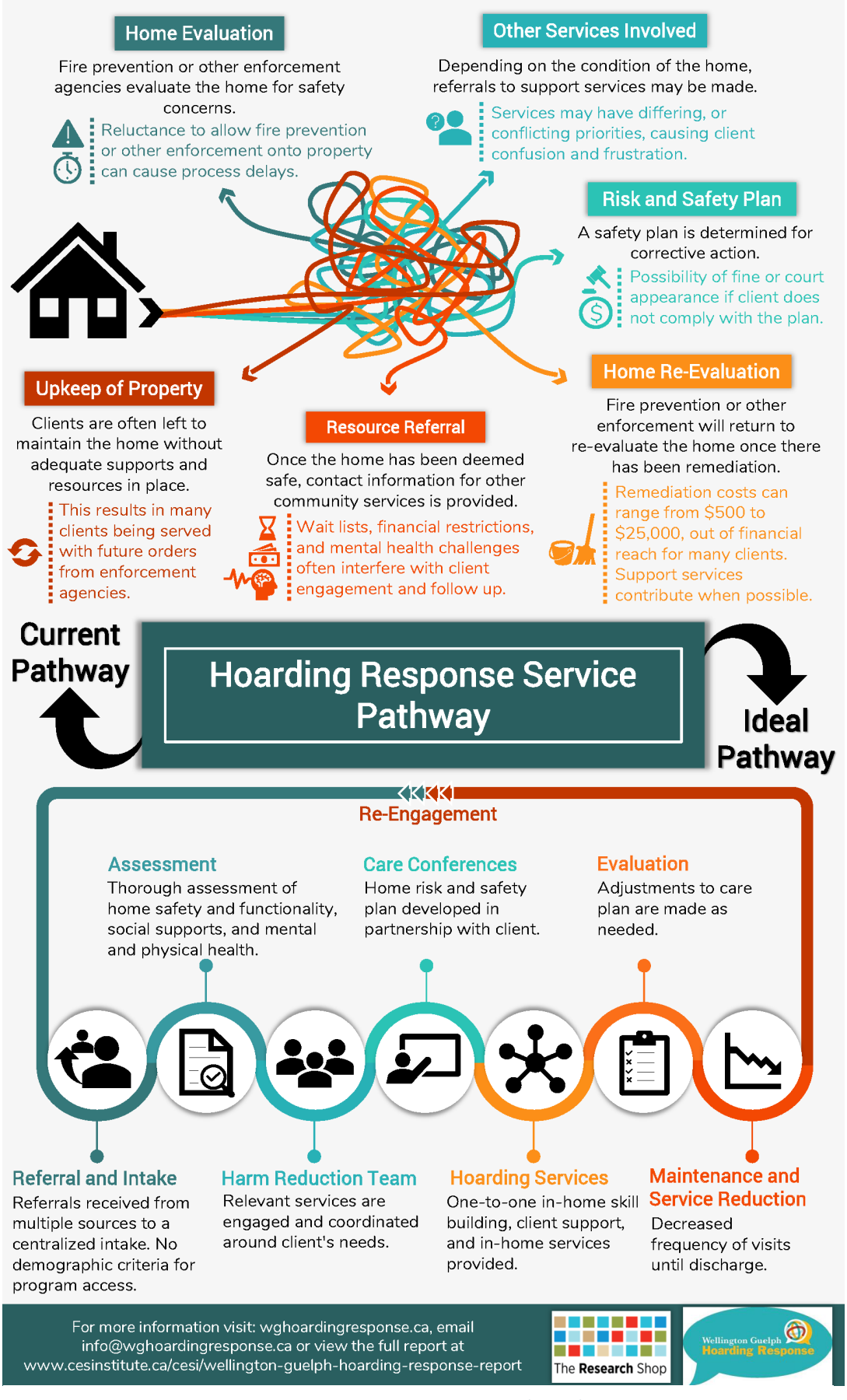
A cross-sectoral approach can improve intervention outcomes because people with hoarding disorder often present with additional vulnerabilities or comorbidities that one service provider cannot adequately approach, including behavioural issues, stigmatization, isolation, housing insecurity, acquired brain injury, physical/mental/neurological issues, and/or drug addiction (State of Victoria, 2013). A 2009 study by the San Francisco Task Force on Compulsive Hoarding (2009) found that 67% of service providers worked with other agencies to support clients with hoarding disorder: survey respondents indicated that the services clients needed the most were related to mental health, case management, education or training for staff, cleaning, and education or training for people with hoarding behaviours and their networks. Importantly, 34% of survey respondents indicated that there were policy and/or bureaucratic bottlenecks preventing them from helping clients with hoarding behaviour, including attorney-client confidentiality, eviction, and capacity concerns.

SERVICE DELIVERY

Identification of and outreach to people struggling with hoarding disorder can be extremely difficult, and strong local networks with knowledgeable staff can strengthen the referral pathways necessary to engage them when they first access supports, even when those supports are not hoarding-related (Bratiotis, Woody & Lauster, 2018). Referral pathways can include community groups, government organisations and service providers, non-profit organisations, and private businesses (Bratiotis, Woody & Lauster, 2018).

Treatment of hoarding disorder requires consistent monitoring of clients and their environment to determine if progress is being made, but resources and capacity have been noted as barriers to sustained monitoring (Bratiotis, Woody, and Lauster, 2018). Monitoring the prevalence of problematic cluttering is further made difficult due to different reporting standards, different by-laws, and subjectivity. Long-term solutions to help manage hoarding disorder is also difficult as relationship building with clients, property managers, and neighbours is also costly and utilises limited capacity (Hanson and Porter, 2021).

FIGURE I



Source: Wellington Guelph Hoarding Response Report (2018).

Service providers have also indicated that there is a significant financial cost to managing clients with hoarding behaviours. For example, Rodger, McDonald & Wootton (2021) note that hoarding disorder requires approximately 20 sessions during active treatment, significantly more than other psychiatric disorders. Additional expenses include pest control, medication and medical supplies, and legal services (San Francisco Task Force on Compulsive Hoarding, 2009). Financial support for clients is also necessary to ensure that those in need of intervention and treatment can access help without significantly impacting their financial stability. This is especially relevant for people with lower and/or fixed incomes.

A 2018 study on service provision for people struggling with hoarding behaviour in Wellington-Guelph, Ontario (Boulé et al., 2018) identified four key issues when addressing hoarding situations: coordination of care, developing trust with clients, securing resources to support clients, and the prevention of a recurrence or high-risk situation (p. 10). The study includes an infographic (see Figure I) that demonstrates current service pathways and proposes an ideal service pathway for supporting clients with hoarding disorder: the ideal pathway includes a project manager, centralized intake, and process plan that coordinates services as needed over time.

LANDLORDS

The effect of hoarding behaviours on landlords needs to be considered in service coordination and delivery as well: when securing tenancy and reducing housing insecurity, landlords and housing providers become key stakeholders in a client's intervention. For example, the San Francisco Task Force on Compulsive Hoarding (2009) found that the effects of hoarding disorder can present significant financial costs to landlords, including pest infestation and animal control, health and safety code enforcement, lost rent, cost to evict, and heavy cleaning. Repair costs are also higher for tenants with hoarding behaviours because of their reluctance to report issues or give repair people access to their apartments. Landlords noted that pervasive odour and the ability to attract other tenants were significant issues as well. Most landlords (55%) in the study felt that rules and policies limited their ability to address hoarding behaviours and placed the burden of health and safety violations on them. A perception that the rental board and fire marshal favoured tenant rights and independence was indicated, and landlords expressed frustration with the responsibility of managing tenants with hoarding behaviours despite not having the resources, knowledge, or ability to help. Engaging with and educating all community stakeholders, including landlords, can facilitate greater empathy, understanding, and acceptance (Bratiotis, Woody & Lauster, 2018).

CONCLUSION

The literature review highlights the profound impact of hoarding behaviour on individuals, their families, and communities. The link between hoarding behaviour and housing insecurity is evident, as it contributes to unsafe living conditions, strained relationships with neighbours,

and financial pressures on individuals, service providers, and landlords. The review emphasizes the web of challenges faced by individuals with hoarding disorder, ranging from compromised mental and emotional well-being to heightened risks of eviction and houselessness. The particular challenges faced by older adults, including challenges related to physical health and the long-term impacts of hoarding behaviour, highlight the need for tailored interventions that address their unique circumstances.

The multifaceted nature of hoarding disorder requires a comprehensive understanding of its implications for effective intervention strategies. The literature supports cognitive-behavioural therapy (CBT) and harm reduction strategies as effective means to mitigate the impact of hoarding behaviours. Case management, especially in the context of an interdisciplinary approach, emerges as a crucial factor in providing holistic support to individuals struggling with hoarding disorder. Service coordination, interdisciplinary collaboration, and community engagement are identified as key components in enhancing the effectiveness of interventions and mitigating the associated challenges.

The literature review underscores the need to address hoarding disorder comprehensively, taking into account its wide-ranging impacts on individuals and the broader community. Effective interventions require a multifaceted, collaborative approach that considers the unique needs of individuals, engages various stakeholders, and strives to create supportive, empathetic communities. Findings from the review emphasize the importance of ongoing research, education, and awareness to develop sustainable solutions for individuals grappling with hoarding disorder and its societal consequences.

DATA ANALYSIS

COORELATION BETWEEN HOARDINGBEHAVIOUR AND HOUSING SECURITY

A key question underlying our research was related to the correlation between hoarding behaviour and housing insecurity: we wanted to learn what proportion of low-resourced seniors who have been identified as living with hoarding behaviour are at risk of houselessness. Response from survey participants was widely variant, ranging from 1-100% (see Chart VI). However, when asked how hoarding behaviour affects the housing security of their clients (Q12), survey respondents indicated a direct link between the two: hoarding impacts the financial security of clients (unpaid bills/rent) and places strain on relationships that can result in the loss of shared housing; concerns related to pest control, air quality, fire safety, and lack of access for repairs/maintenance and/or egress for first responders create tension with neighbours and landlords, who may pursue enforcement options and/or eviction. One respondent referenced clients who are already houseless as a result of their hoarding behaviour. Survey participants indicated that imminent risk of eviction, housing precarity, and

unsafe living conditions were key identifiers for housing insecurity (see Chart VII). The (physical and mental) health and safety of an older adult living in a hoarded home also impacts housing security: one respondent indicated that a home may be considered unsafe because of frailty or cognitive issues, and another noted that mental and cognitive health can deteriorate as a result of eviction.

CHART VI

Q10: Approximately what % of your participants with hoarding behaviour experience housing insecurity?

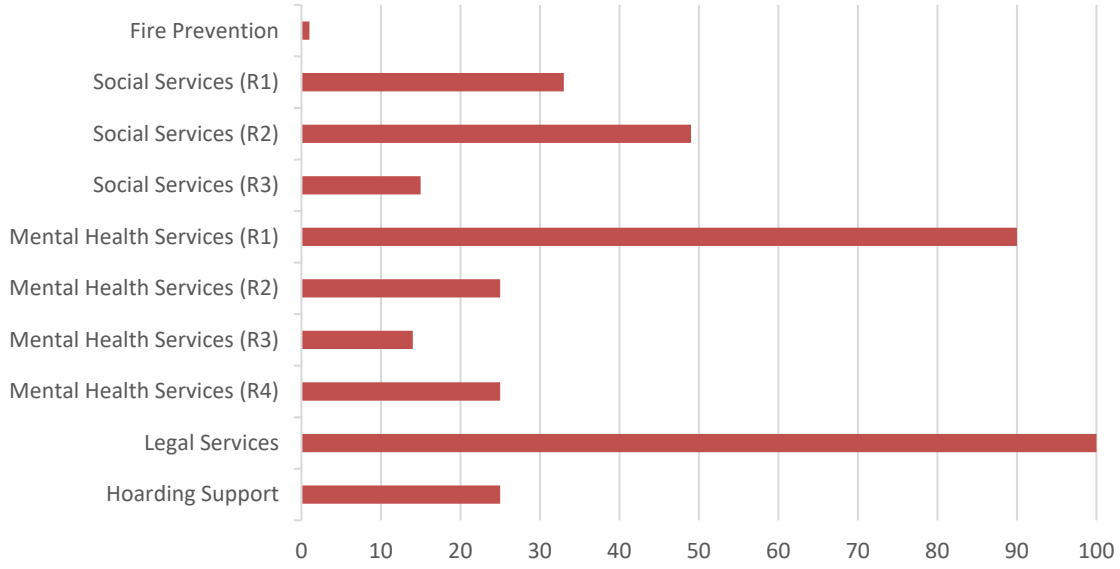


CHART VII

Q11: Can you elaborate on how you assess or determine housing insecurity?

Interviews participants working directly with clients who struggle with hoarding behaviour identified a much stronger link between the disorder and housing insecurity. Seniors are often identified by service providers as living with hoarding behaviour *because* they are experiencing housing insecurity and their condition has been revealed during an assessment process. Seniors are also more likely to reach out for help only once the threat of eviction is imminent. This is significant, because the primary driver is not a desire to address their hoarding behaviour: they are compelled to seek support as a result of the crisis.

"We know that this particular clientele, the biggest barrier that we run into is that they are so isolated and they are so closed off, and they've taken years to create that. These are people that don't want to be seen in the community. These are people that don't reach out because they need support. They do the exact opposite. They close all the windows, they shutter up the blinds, they close the doors, they don't answer the phones, they don't come to the door."

A number of interviewees referenced the 'Carrot and Stick' approach, where the threat of eviction is a 'stick' that compels the senior to seek an intervention for their hoarding behaviour, and the hoarding program is the 'carrot' that keeps them housed - landlords will often delay eviction on the condition that the senior is working with a program and progress is reported. Therefore, it is the housing crisis that becomes centred in the intervention, and the hoarding program is the mechanism by which it is resolved. This is indicative of the way in which housing security is centred as the primary concern of hoarding disorder for service providers: the goal for hoarding interventions is to prevent eviction and that is a key marker of success.

For example, one interview participant detailed a form of case management focused specifically on decluttering events whereby a decluttering team works with the client and a group of volunteers before (to prepare them for the decluttering event), during (to undertake the actual decluttering), and after (to debrief the decluttering) the event. This approach employs disaster psychology to hoarding cleanouts and is based on training received through the Centre for Clutter and Hoarding (Safety Day: An Application of Disaster Psychology to Hoarding Cleanouts). This intervention has the potential to help mitigate the trauma experienced by the client during the decluttering event, but because it is focused on the impact of the hoarding behaviour (the hoard/home), it is not sufficient to address the hoarding disorder itself. After-care and support is extremely limited, and primarily focused on managing the impact of the decluttering event itself.

"The site manager was the was the stick for them and [the case manager] was the carrot because she had knowledge about hoarding behaviours, and she could come with that approach that, 'Okay, like, these are the guidelines that your building manager wants. What can we do to help you? What can we do to support you to get there?' So, it seems like a manipulative relationship, but it's not. It's all about, you know, 'This is what's out there and we want to be able to support you and be able to access it.'"

To effectively address hoarding disorder, sustained support that considers the underlying or correlated mental health concerns and other quality of life needs (e.g. physical health, financial security) are required post-intervention. Post-crisis case management and peer and/or mental health support is necessary to prevent a recurrence. Interview participants noted that the acquiring behaviours resulting from hoarding disorder are a coping mechanism that mirror the addiction cycle, and part of the treatment plan needs to include strategies for managing life stressors. When someone is triggered, acquiring items can bring a feeling of relief or joy, which is soon replaced by a sense of guilt or shame for the behaviour, and leads to more acquiring. Importantly, the crisis intervention itself can act as a triggering event and compound the desire to acquire and retain items, and without post-crisis treatment or support, most people will simply start the cycle again.

It is worth noting that seniors dealing with the effects of hoarding behaviour do not always become visible to the system as a result of a housing crisis. As people age, they may be motivated to address their hoarding behaviour because they are concerned that declining health may prohibit them from doing so in the future. As a result, their entry point will be different, but they will nonetheless require long-term support to manage their disorder.

Interview participants shed light on crisis-centric interventions that lack a comprehensive approach to addressing hoarding disorder over the long term. Hoarding interventions within a system of supports that is primarily focused on dealing with the symptoms of hoarding disorder (managing the hoard and making sure people remain housed), can only address the mental health concerns and correlated vulnerabilities as needed to help resolve the crisis. The net effect is that the intervention, which is resource-intensive and expensive, becomes part of the cycle and practically guarantees another intervention will be required later on. To break the cycle, sustained support that addresses underlying mental health concerns and other needs are required post-intervention. Post-crisis case management, peer support, mental health services, and addiction treatment are identified as crucial components to prevent recurrence and increase housing security.

It is also worth noting that interview participants indicated that housing security for seniors needs to include a consideration of 'appropriate' housing. Through the assessment and

"Hoarding disorder is very rarely the only issue that these people come to us with. These are typically complex cases. Because hoarding disorder is a mental illness, we know that it's rarely standalone; it also comes with other mental illnesses as well, a major one being depression."

"[If] the timeline is two days to make the place amenable to the landlord, you can just imagine there's not much control over the situation from the participant…if we get notice six months even, in advance, and there was the opportunity to be able to make those changes on a longer timeline, we know that those interventions are less traumatic."

intervention process, physical and/or mobility needs can be identified that require the senior to move into supportive living or other housing that provides a higher level of care. Long wait times for subsidized housing in these areas can increase the seniors housing insecurity if their current rental situation is compromised by their hoarding behaviour.

IMPACT OF HOARDING BEHAVIOUR ON HOUSING SECURITY

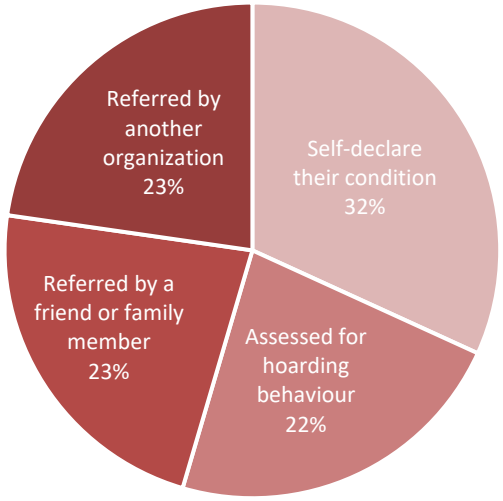
The impact of hoarding behaviour on housing insecurity for older adults is straightforward and significant: for seniors facing eviction, addressing the hoard (decluttering) is a condition of their ability to remain in their home. This in turn has a profound impact on the nature of the intervention that results: when clients are identified because of an imminent housing crisis, it is the crisis that becomes the focus of the intervention. But the housing crisis is rarely (if ever) the only issue: for example, survey respondents indicated that 23% of older adults with hoarding behaviour are referred to their programs by other organizations (see Chart VIII), including home care, hospitals, nurses or social workers in medical settings, mental health professionals, landlords or housing providers, and fire crews. Clients are also identified when they are accessing support for other reasons (e.g. cognitive issues, tenancy/legal concerns), and in-home visits/observation. It is worth noting that although there are standard tools to assess a hoarding concern (e.g. Clutter Image Scale), these do not seem to be used consistently: when asked how they assessed for hoarding behaviour, only two out of 11 survey respondents indicated that they use standard assessment tools (HOMES Scale or Clutter Image Rating Scale). Other assessments include observation (4), other forms of assessment (3), and interviews with clients (2). These findings were corroborated by interview participants, who indicated that deciding whether an intervention is required and/or what that intervention will be is often either a judgment call or driven by other factors (e.g. threat of eviction).

The complex nature of hoarding disorder was highlighted by interview participants: in addition to the mental health concern that underlies the hoarding behaviour, the client is also likely dealing with deep isolation and loneliness, depression and/or anxiety, financial insecurity, and/or physical health concerns. These things are addressed as part of a holistic approach

employed by the case managers, but without sustained support the senior is quite likely to find themselves at risk again.

CHART VIII

Q7: How do you identify participants who struggle with hoarding behaviour?



The long-term success of an intervention is often dependent on four intersecting factors: time, a sense of control, motivation, and insight. First, the inability to be part of the decision-making process will create anxiety for clients, many of whom will already have had an experience where a well-meaning person has attempted to clean out their space despite their protests. Making the decision to discard items can take a significant amount of time for clients, because they are struggling with an unhealthy attachment to their things that is rooted in their hoarding disorder. Decision-making can be facilitated by a case manager most effectively once they have established a rapport and trust with the client, which also takes time, but can increase the potential that the client will gain insight into their condition and become intrinsically motivated to address it. The extreme time constraints tied to a crisis-intervention approach focused on preventing eviction limits control for (and re-traumatizes) the client, significantly reduces the potential for insight and motivation to develop, and essentially ensures that they will reach the crisis point again.

The case management model is largely effective because it is relational in nature: case managers establish rapport with people who have been isolated by their disorder and help them be safe and healthy in their homes without removing control or decision-making power from them. Seniors with hoarding disorder are very likely to have experienced a negative or traumatic intervention at some point, and are often referred into programs by somebody else (e.g. landlord), so building rapport and trust with the client takes time. Case managers will target the intervention to specific areas and tie it to a particular purpose (e.g. safety, function, egress) which can increase cooperation from the client, who feels like they are a part of the decision-making process. In this way, harm-reduction is used to help keep control and decision-making in the hands of the senior.

"[Control over decision-making] is a key to success, but it's timely. Like, it's time consuming, so to try and pressure somebody who's already struggling with anxiety to make those decisions within a two-day frame, or, you know, what an emergency intervention typically takes, you can just imagine that's not going to be long-lasting change."

"Previously somebody tried to assist them and they decided to just go in with a shovel, clean everything up, wipe everything down, put everything back nice, neat, and tidy. We know that doesn't work...from research and personal experience, we know that that's actually more detrimental to our clients than not doing anything at all."

Hoarding disorder is essentially an anxiety disorder, and successful treatment[2] also requires the time it takes to manage the client's anxiety around discarding items to which they are unhealthily attached: CBT therapy is used to focus on small manageable goals, address the correlated anxiety, and motivate them to continue the process. While CBT is a slow, long-term treatment process, it keeps control and decision-making with the senior while addressing the immediate issue and building toward better outcomes in the long-term. Effective post-crisis treatment includes addressing the core reasons for the behaviour: this has the greatest potential for the client to develop insight and motivation to change, which will ultimately lead to better outcomes in the long-term.

Participation in post-crisis treatment is voluntary and can include participation in peer support groups and/or other mental health related programs (e.g. living with depression), programs using the Buried in Treasures self-help book, and CBT. Peer support groups can be extremely important, as clients are very likely to be isolated and the groups offer connection, acceptance, and understanding through shared experience. Interview participants did note however, that the motivation to attend a program or support group to discuss their hoarding behaviour does not mean that a client will be ready to act and address it (declutter). In one example, participants complete a 15-week program and then have the option to attend one of two support groups (online or in-person). Support group participants volunteer to meet online (with their cameras on), set a timer and clean, and then come back together to debrief their experience: the greatest attrition (20-25%) for this program occurs when the focus moves from discussing the hoarding behaviour to actively decluttering.

[2] When discussing their work with clients, interview participants often conflated treatment with case management and after-care. This is noteworthy, because now that hoarding disorder is part of the DSM, 'treatment' might be mistaken as medical or mental health care, but in this instance generally refers to peer support and CBT programs.

"I had one [client] where I had followed her from a couple different houses, and yeah, she always just destroys the place. I've closed her house multiple times with closure orders. But the last time…we had a bunch of other supports that weren't there the first two times that we got in place. Is she going to have a clean place? No. But she'll have a lot of people keeping an eye on her and making sure it never reaches the levels it had in the past."

"Also, it's part of that kind of early intervention, prevention and harm reduction kind of approach, which is, this person is going to continue to hoard. We need to keep them from getting into an unhealthier crisis situation."

It is important to acknowledge that while the housing crisis is often the point of entry for intervention and treatment, it cannot be the sole focus: the hoard must be dealt with, but it is rarely the only problem - the senior is also very likely dealing with physical, mental, financial, and other concerns that need to be addressed. The underlying or co-existing conditions (e.g. anxiety, depression) that drive the behaviour must also be considered: for example, a senior who is struggling with depression may be experiencing a lack of motivation that prevents them from addressing their hoarding behaviour. This requires a holistic approach to long-term case management that includes, but extends beyond treatment for the hoarding behaviour.

Because the current system is centred on the symptom (housing crisis) and not the condition (hoarding disorder), that is where the bulk of funding is spent: there is little money for after-care, which in one example is spent on helping the client manage the impact of the crisis intervention itself. But hoarding disorder is a chronic and progressive illness and the recidivism rate is quite high, which underscores the need for long-term treatment and support. The need for long-term supports, including low- or no-cost assistance with regular de-cluttering and organizing and mental health supports, for example, was identified by several survey respondents.

EFFECTIVE INTERVENTION

Interview questions related to the types of intervention provided the most insight into the nature of housing insecurity as it relates to hoarding disorder, because it highlighted systemic issues that need to be addressed in order to 1) increase housing security amongst people struggling with hoarding behaviours, and 2) decrease the impact it has on the community.

The interviews revealed two different community-based approaches to addressing hoarding behaviour.[3] The first is the collaborative approach taken in Edmonton, where representatives from different stakeholder groups come together as part of the Edmonton Hoarding Coalition

[3] Calgary does not currently have a collective community-based response to hoarding disorder.

"That doesn't mean that we can't be successful when they are [facing eviction], when people are coming to us in that kind of duress. We just have to work twice as hard for follow-up. Follow-up is even more important to be able to kind of mitigate the damage of that short time frame. So, at the very least, if we can't have the preventative measures in place to begin with, then we have to, for sure, ensure that we have follow-up support after this type of a dramatic event in their life."

"And then the [case manager] kind of keeps their file open and periodically checks on them to make sure things are going good. That's something that [our organization] would never do. Once we get it cleaned up, we're done. We'll never really check on them that often unless we get more complaints or something. The case manager thing definitely helps with that. It definitely improves a lot of people's lives, and we've saved people's lives multiple times too."

(EHC) to identify supports for clients, share knowledge and identify resources, and raise awareness of hoarding behaviour. The second approach is employed by Lethbridge, where the Hoarding, Outreach, Management, & Education (HOME) Team works to help individuals address their hoarding behaviour and quality of life, coordinate interventions and supports, and act as a resource for individuals and agencies. In the Lethbridge example, a case manager with expertise addressing hoarding behaviour is funded through and employed by a non-profit subsidiary of the Lethbridge housing authority: the case manager helps to coordinate Lethbridge's response to hoarding, provides holistic support for people struggling with hoarding behaviour, and acts as a point person for the program.

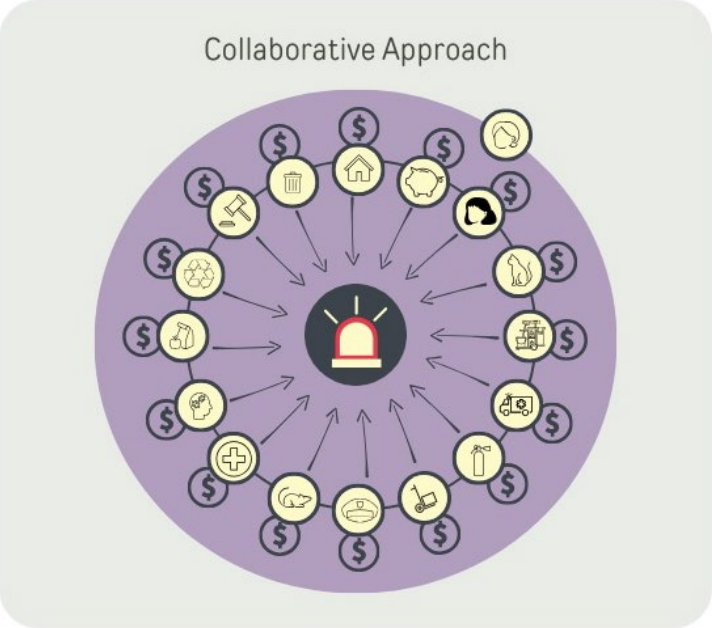
The Edmonton Hoarding Coalition formed as a community-based response to the impacts of hoarding behaviour, but is not funded: this means that there is no backbone support (e.g. planning, communications, evaluation, administration) for the work, and systems change and process improvement is largely ad hoc. The coordinated model in Lethbridge internalizes the benefits of the collaborative approach (shared purpose, relationship building, cross-sector collaboration), but leverages the case manager to foster relationships, build resources, broker cross-sector collaboration, and inform systems-level processes that improve efficiencies.

Case managers in both models have a particular expertise in dealing with hoarding behaviours and navigating the system of supports that can help to keep clients safely housed. Once the individual has been identified as a result of their housing crisis, case managers in both models employ a holistic approach that addresses other areas of concern. Advocacy and service coordination are central to the roles of the case manager when responding to the housing crisis, but hoarding behaviour is rarely the only issue, and case managers work to "stabilize" the person as much as possible. In addition to coordinating family members, volunteers, and others involved in the decluttering

event, their work typically includes helping people access the resources that are available to them, including financial supports (to address the crisis and longer term income security), mental and physical health services (including home care), and programs geared toward increasing food security and decreasing isolation. Case managers also provide guidance, support, and education for family members and landlords dealing with someone who is struggling with hoarding disorder.

A critical difference between the two is the role these case managers play at the systems level: in Edmonton, case managers represent individual organizations and work collaboratively with other coalition members on a case-by-case basis (see Figure II); in Lethbridge, the case manager 'owns' the hoarding portfolio and works to support both individual clients and the organizations involved (see Figure III). In Lethbridge's coordinated model, an established referral pathway triggers a case manager who has expertise related to hoarding disorder and knows how to navigate the system of supports. The case manager then takes over and relieves the initial service provider from responsibility for the concern. The referring organization may continue to be involved (approximately 25% of the time), but only in a supporting role as appropriate.

FIGURE II

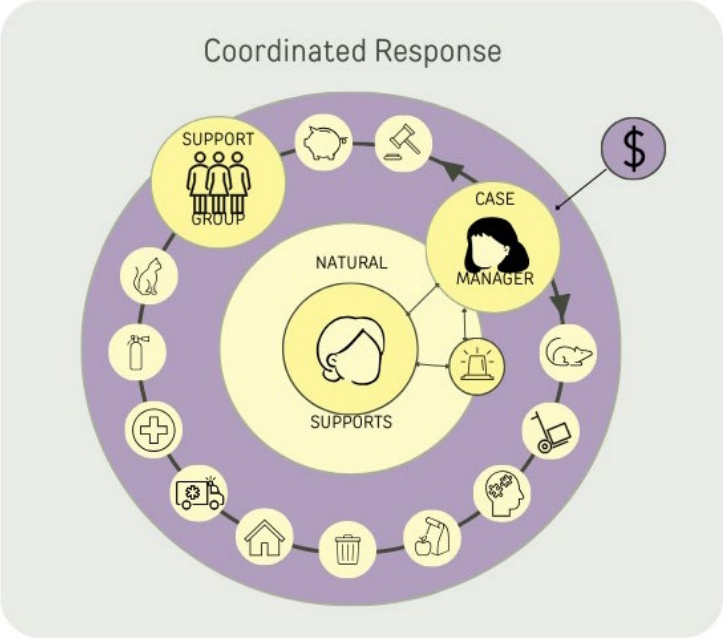


The case managers in both approaches have expertise, connections to resources, an ability to broker and advocate, and a relationship with the client that can be sustained once crisis has been resolved. But the stop-gap nature of the collaborative approach in Edmonton means that the resolution of the crisis effectively closes the case, and success is measured primarily as the prevention of imminent houselessness. In the Lethbridge example, the client is generally identified because of the housing crisis but remains a part of the case manager's case load even once that crisis has been managed, although the number of interactions will decrease and may simply involve regular check-ins to prevent escalation. A file may close if the senior has been moved into congregate living, or the individual has been connected to supports (e.g. home care) who can make the HOME team aware of an impending concern. The case manager will also close a client file when the person is no longer visible to them (approximately six months

with no contact), but because the HOME team is aware of them, the file is not so much closed as dormant (e.g. organic and non-invasive check-ins).
In Lethbridge, the case manager position is funded through the housing and houselessness program, and that dedicated funding helps support system coordination, awareness, advocacy, and intervention. It also means that the approach is essentially a housing first (but not last) strategy that acknowledges that the problem is not likely to go away - it can only be managed.

While control and motivation to address the hoarding behaviour remains with the client, both interview participants working within the Lethbridge model referenced the importance of sustained surveillance post-crisis. The ability to "have eyes" on clients in non-invasive ways can prevent an escalation to the pre-crisis state: it is a form of system-level harm-reduction that focuses on providing hoarding and non-hoarding related supports that improve the quality of life of the client and stabilizes their situation over time. For example, arranging for food delivery through Meals on Wheels not only improves the food security of the senior, but ensures that there is someone who knows to contact the HOME Team if they become concerned about their client's living conditions. It is a coordinated effort focused on prevention, and employs a sustained harm-reduction approach that recentres the senior after the crisis has passed.

FIGURE III



In both models, the case manager is able to stabilize 75-80% of clients. Because the onus is on the senior to initiate treatment for their hoarding behaviour, post-crisis support might simply begin as a trusted (if inactive) relationship: employing a harm-reduction approach that addresses the needs of the whole person during the crisis can establish a baseline of trust that may be drawn upon later. The person who has experienced the crisis is likely to be struggling with shame, anxiety, and/or depression as a result of their condition and may have been re-traumatized by the decluttering event. The case manager and/or hoarding program can be a safe option for the senior to leverage when they are ready to address their situation. The critical difference is in the system-level coordination made possible by the case manager in the

Lethbridge example: clients remain visible to the system of supports, and even though they may continue to hoard and require further intervention, the problem will not be as severe in subsequent instances.

Another difference between Edmonton and Lethbridge is evident in their approach to awareness-raising: in Edmonton, coalition members give presentations, host a website, and otherwise try to raise public awareness of hoarding behaviour and its impacts. One of the organizations working with the EHC has received funding to create a network of resources and agencies, undertake capacity-building, and offer training based on their intervention. In Lethbridge, HOME team organizations work to improve systems and educate staff and stakeholders about hoarding disorder in accordance with their work. For example, a checkbox to flag potential hoarding concerns has been added to forms used by Bylaw Officers, and this would require bylaw enforcement to embed information on what it is, why it is there, and what happens when it is checked into existing training and onboarding processes. With this approach, awareness efforts can be diffused across all stakeholder groups in the way that is most relevant to them.

It is worth noting that because they are employed by the housing authority, the case manager in Lethbridge is working as part of that organization's internal structure: when encountering hoarding issues, other members of the organization are not 'referring out', they are working with the case manager on a housing issue as part of a Housing First strategy, and this may improve the quality of the interventions. And while the lack of financial resources to support the logistics of an intervention (e.g. junk removal, storage) is problematic in both cases, the lack of sustained funding for case management and coordination in the Edmonton model means that a significant amount of time is spent trying to secure funding for the program itself.

SYSTEMIC BARRIERS

Interview participants were asked to identify key systemic barriers they face when working with older adults who are struggling with hoarding behaviour. The lack of resources to undertake cleaning and decluttering, support programs, and mental health supports were all identified as priorities.

" The confusion piece is real: trying to find the right resources is challenging even when you don't have mental health issues – never mind someone who already has barriers."

There is currently limited funding to address hoarding in Edmonton, and most organizations are working 'off the sides of their desks' to do so. The financial support that is available is tied to crisis intervention: continued funding to help clients maintain their space post-intervention would help prevent another crisis, but is not currently available. A significant challenge for both models (Edmonton and Lethbridge) is trying to secure the resources needed to help with decluttering, and a lot of time

can be spent trying to access funding for clients through income supports. Clients experiencing a housing crisis as a result of their hoarding behaviour are very likely to be financially insecure and are not able to pay for decluttering, storage, cleaning, and/or post-intervention maintenance. This problem is exacerbated for seniors, who are also likely to have physical health issues that limit their ability to undertake the work themselves (e.g. lifting; hauling).

Accessing community-supports takes time, and not having adequate resources can exacerbate the trauma experienced by the client during the intervention. A correlated concern is the general decrease in volunteerism that has impacted the non-profit sector since the onset of COVID-19, as community-based responses to hoarding rely heavily on volunteers to support the work.

There is also a general lack of affordable housing, and wait lists can be prohibitive. And for older adults who may need to move into higher levels of care as they age, their untreated hoarding disorder can prevent them from accessing supportive living, which leaves them no option for safe, appropriate housing.

Interview participants indicated that the lack of coordination at a systems level creates confusion and unnecessary bureaucracy, which can be particularly difficult for people facing a crisis and dealing with multiple barriers. For example, in Edmonton, Alberta Health Services (AHS) has a staff person working with hoarding clients, but that is not widely known across the organization. This is compounded by a limited awareness and understanding of hoarding disorder more broadly, which creates challenges with landlords, the court system, and others.

The classification of hoarding as a stand-alone disorder the DSM-5 (2013) was a significant step toward reducing housing precarity, in part because it provides the baseline for a human rights argument in court when clients are facing eviction. Due to its clinical designation, hoarding disorder can be considered a psychiatric disability that landlords must accommodate under the Alberta Human Rights Act. The argument can be made with the Residential Tenancy Dispute Resolution Service (RTDRS) that eviction cases and appeals must be transferred to the Court of King's bench, which is better positioned to consider hoarding disorder as a disability, and therefore treat it as a human rights issue. This generally results in an extended timeline for the client to address key concerns and remain housed, which can improve the probability that the client will be successful. At the RTDRS, where the human rights issue is not considered, clients are more likely to be given an extremely short period of time (e.g. one week) to resolve the issue, which inevitably leads to eviction. The process of appealing to the RTDRS to transfer each case to the provincial court is time consuming and expensive – and there are limited resources and lawyers available to facilitate it effectively. This represents a critical systemic barrier that could be overcome if eviction cases related to hoarding were deferred to the provincial court automatically.

Interview participants also discussed barriers related to the policy requirements of different organizations from multiple sectors, including those related to confidentiality and insurance, which can impede information-sharing and collaboration on individual cases. This is somewhat mitigated in the Lethbridge model, where the case manager acts as the point-person and can protect the privacy of the client.

SUMMARY

Interview participants reinforced the link between hoarding behaviour and housing insecurity for low-resourced seniors. The imminent threat of eviction often propels older adults to seek help, which, when coupled with limited program resources, centres the housing crisis in the intervention, rather than the hoarding disorder itself. The 'Carrot and Stick' approach referenced by multiple participants (where the threat of eviction acts as the 'stick' and participation in a hoarding program is the 'carrot') exemplifies the centrality of housing insecurity in current interventions: the primary focus remains crisis management rather than long-term behavioural change, and the likelihood of recurrence is high without sustained support post-intervention. Post-crisis case management, peer support, and mental health services were identified as crucial components of treatment for the disorder and prevention of another crisis.

Two community-based approaches illustrate different models for addressing hoarding behaviour: the collaborative approach taken in Edmonton, and the coordinated model employed by Lethbridge. Case managers play a pivotal role in both models, addressing immediate concerns and coordinating resources: the relational and holistic nature of case management and a harm reduction approach are used to address intersecting vulnerabilities and build trust with clients. Harm reduction is identified as a crucial strategy because it reduces distress for individuals and their networks while mitigating the health and safety risks associated with hoarding. A harm reduction approach also supports healthy aging in place among seniors, addressing the specific needs of this demographic.

The complex challenges faced by older adults struggling with hoarding disorder require a comprehensive, long-term approach that goes beyond crisis management. By addressing root causes, providing sustained support, and coordinating efforts at the community and systems levels, interventions can aim not only to prevent immediate houselessness but help seniors to manage their hoarding behaviour, improve their overall well-being, and support healthy aging in place.

Systemic barriers, including limited funding, lack of affordable housing, and bureaucratic challenges, hinder effective interventions. A coordinated, systems-level approach, streamlined

referral pathways, and standardized reporting systems are proposed solutions to enhance efficiency and efficacy when addressing hoarding disorder and housing security in older adults.

Lethbridge's coordinated model has the potential to create significant efficiencies and improve the effectiveness of hoarding programs. While crisis intervention is often a necessary first step, it cannot be the only step. A coordinated model can prevent re-escalation by engaging in long-term, client-centered case management. Post-crisis engagement and support is vital for preventing another crisis and support the wellbeing of the senior.

CONCLUSION

In 2013, Sage Seniors Association released a report proposing an integrated community response to hoarding that involved a comprehensive case management approach with a program manager, central intake line, standardized referral and assessment tools, a services roadmap and public education plan, and an inter-agency coalition (Sage Seniors Association, 2013). The report concluded that coordination of services would increase access, improve system-level efficiencies and decrease the burden of complex cases on individual organizations, and called for dedicated funding to sustain an integrated response to hoarding over time. This report draws the same conclusions, and recommends investment in a coordinated approach to addressing the impacts of hoarding disorder on older adults and their communities.

The correlation between hoarding behaviour and housing insecurity among low-resourced seniors necessitates a shift in focus from crisis intervention to sustained support. Hoarding behaviour is rarely a standalone issue, and intervention strategies must address the complex nature of cases and prioritize healthy aging in place. Bratiotis, Woody, and Lauster (2018) argue that an interdisciplinary case management model helps communities and stakeholders recognize that individuals with hoarding disorder require support akin to those experiencing other mental health issues. By adopting a holistic approach that combines crisis management with long-term support, policymakers and practitioners can effectively address the root causes of hoarding disorders among seniors, and better support their well-being and housing stability.

The collaborative approach to hoarding employed by Edmonton organizations (see Figure II) is largely a response to the lack of dedicated funding for hoarding interventions: participating organizations are working together to address the needs of a highly vulnerable population, often off the sides of their desks. The result is that extremely limited resources need to be focused on the most critical concern: the housing crisis. Case managers address other needs when possible to stabilize the client, but the nature of the disorder means that without sustained support, the people affected by it will almost inevitably find themselves in crisis again. Investing in post-crisis care would allow the case manager and other stakeholders to address the factors that surround the hoarding behaviour, and increase the likelihood that the

senior will address the condition itself. Continuing to focus on the symptoms of the disorder (i.e. housing precarity) almost guarantees that the crisis will happen again.

The problematic nature of the crisis intervention approach is rooted in the need for time, insight into the problem, and motivation to change that is required for the senior to address their hoarding behaviour. A crisis intervention undertaken within a short timeline to prevent eviction can threaten or restrict a client's decision-making and control, and greatly reduce the potential for insight and longer-term motivation to develop. It is also more likely to be a traumatic experience for the senior, which may re-entrench their need to hoard and increase the probability that their acquiring behaviours will lead to another crisis.

Because older adults with hoarding disorder are largely not going to be visible to the system until the point of crisis, the system needs to focus on long term after-care and the opportunity to prevent a recurrence of the crisis state. Time is a critical factor in addressing hoarding behaviour: it is required to build trust, develop insight and motivation, and allow for decision-making to occur at a pace the client is comfortable with. As a result, an effective intervention model needs to internalize the understanding that substantive change is not going to happen first time the crisis arises, but could be used as a catalyst to prevent subsequent occurrences. Again, effective treatment for hoarding disorder requires motivation, insight, and decision-making control on the part of the client: that cannot be built into the system of supports. What can be embedded is the time it takes to build a trusting relationship and opportunities to seek treatment when clients choose to do so.

Case management, while effective, is resource-intensive and requires high levels of inter-professional cooperation. The barriers to finding information and seeking help further complicate the delivery of services, making it challenging for individuals and service providers alike. To enhance the effectiveness of interventions, Hanson and Porter (2021) advocate for a standardized reporting system to streamline information, and emphasize the need for systems-level changes to establish best practices and facilitate coordination among service providers. The coordinated model used in Lethbridge is an effective way to organize a community response to hoarding that effectively leverages case management to meet these goals (see Figure III). Coupled with the Hoarding Response Service Pathway proposed by the Wellington Guelph Hoarding Response Report in 2018 (see Figure I), the coordinated model has the potential to prevent re-escalation to crisis and significantly improve outcomes for older adults struggling with the effects of hoarding behaviour.

Beyond the impact that it has on the wellbeing of older adults, hoarding disorder poses environmental and health risks, and places a substantial economic burden on community-based organizations, housing providers, and emergency services. While the total cost of hoarding behaviour is difficult to quantify, the San Francisco Task Force (2009) identifies various financial

impacts, including healthcare, housing, safety, legal, and social service costs. The true value of coordination rather than collaboration lies in its ability to streamline processes at the systems level that are geared toward prevention rather than intervention. This is not only beneficial for the clients and the people who work with them, but has the potential to be fiscally beneficial at a systems level as well. Further research to determine the actual economic impact of sustaining the current crisis intervention model compared to the long-term potential of a coordinated approach to community-based responses to hoarding could improve advocacy efforts in this area.

Addressing hoarding disorder requires a comprehensive and coordinated approach that encompasses harm reduction, case management, and systemic changes in service delivery. The coordinated model can support this work by embedding standardized referral pathways into existing processes and systems, adopting interdisciplinary case management models, and promoting harm reduction strategies, so that communities can better support older adults with hoarding behaviours and reduce the economic burden on society.

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APPENDIX I

Community-based Hoarding Supports across Canada

LOCATION	ORGANIZATION/PROGRAM	OFFERED
British Columbia		
Vancouver	The Centre for Collaborative Research on Hoarding	Collaborative that conducts research and provides resources https://hoarding.psych.ubc.ca/resources/provincial-resources/
Vancouver	Hoarding Action Response Team (HART)	Provides a coordinated community response to those impacted by hoarding https://vancouver.ca/people-programs/hoarding-action-response-team.aspx
Vancouver Island	Vancouver Island Hoarding and Clutter Support	Facebook Group offering support and sharing for those struggling with clutter https://www.facebook.com/groups/5543978683 29164/
Victoria	Hoarding Education and Action Team (HEAT) Online Support	Online support offered through the Vancouver Island Hoarding and Clutter Support Facebook group https://www.islandhealth.ca/our-services/hoarding-services/hoarding-services-heat
Victoria	HEAT Online Support Peer Zoom Meetings	Support group for people struggling with clutter or hoarding behaviours
Alberta		
	Hoarding Disorders Foundation of Alberta (HDFA)	Provide supports and services for people who struggle with hoarding behaviours and their loved ones https://www.hdfa.ca/
Calgary	Carya Senior Support - Making Room: A Hoarding Support Group	Group for older adults experiencing difficulties with clutter, excess acquiring and/or difficulties discarding https://caryacalgary.ca/our-programs/older-adults/making-room/
Calgary	Elements Calgary Mental Health Centre	Decluttering program: must be 18+ and have a diagnosed mental illness as primary presenting condition https://elementscmhc.ca/referral-form-and-our-programs/decluttering/
Edmonton	Sage Seniors Association: This Full House	Support and system navigation for seniors (aged 55+) who struggle with compulsive hoarding behaviour www.mysage.ca/help/this-full-house
Edmonton	Edmonton Hoarding Coalition	Community partners working together to address the experiences and needs of individuals living with hoarding behaviours https://www.edmontonhoardingcoalition.ca
Lethbridge	Hoarding Outreach Management & Education (HOME) Team	Collaborative partnership raising awareness of hoarding, and safe housing by developing and implementing best practices and intervention strategies https://lethbridgehousing.ca/hoarding

Saskatchewan		
Saskatoon	Saskatoon Housing Coalition Self-Help Hoarding Group	Weekly self-help support group for individuals with issues around hoarding https://www.saskatoonhousingcoalition.ca
Manitoba		
Brandon	Prairie Mountain Inter- Agency Hoarding Coalition	Provides collaborative leadership, assessment, and coordination to respond to and prevent incidents of severe hoarding or domestic squalor https://www.prairiemountainhealth.ca/healthy-communities
Winnipeg	A&O Support Services for Older Adults: This Full House	Helps individuals 55+ experiencing hoarding behaviours to live safely in their home https://www.aosupportservices.ca/our-three- pillars/safety-security/this-full-house/
Ontario		
Hamilton	Catholic Social Services of Hamilton Gatekeepers Program	Works in conjunction with health and social service community partners to identify seniors living in severe self-neglect (Diogenes Syndrome) https://cfshw.com/gate keepers/
Peel Region	Coalition on Hoarding in Peel (CHIP)	Supports community members who experience social and health issues related to hoarding disorder by advocating for wrap-around services and a coordinated approach to service delivery https://www.homelesshub.ca/blog/hoarding-region-peel-collaborative-response-complex-issue
Toronto	Toronto Hoarding Support Services Network (THSSN)	Group of 16 agencies working together to provide mental health and short-term case management to address problematic hoarding https://www.torontohoardingnetwork.ca/
Toronto	Home Health Care Clutter and Hoarding Support Therapy	Help individuals with hoarding behaviour remain housed and safe https://www.vha.ca/services/clutter-hoarding- support-therapy/
Sarnia-Lambton	Home Response Collaborative - Vulnerable Seniors	Intervention services for vulnerable older adults (including unsafe or unsanitary living conditions, high risk for eviction or becoming homeless) https://www.hrcsarnia.com/
Wellington Guelph	Wellington Guelph Hoarding Response	Group of organizations providing support and resources for persons with hoarding challenges https://wghoardingresponse.ca/
General	Hoarding/Cluttering Support Group Facebook	Provides tools, education, information, and support for everyone impacted by Hoarding https://www.facebook.com/groups/hcSupportGroup/

APPENDIX II

Survey

INTRODUCTION AND CONSENT

Sage Seniors Association is researching the effect of hoarding behaviour on low-resourced seniors (aged 55+). Through this survey, we seek to collect aggregate-level data to better understand how hoarding behaviour is correlated with housing insecurity and other precarious situations such as homelessness and poverty. You have been invited to complete this survey because we believe your insight and expertise are paramount to achieving the objectives of this research project. This survey will take approximately 15 minutes to complete. Please note: this survey is not timed, but should be completed in one sitting. If you close the survey link before submitting, your responses will not be recorded.

When answering these questions, please consider primarily low-resourced seniors (aged 55+), although we may collect other demographic information. Low-resourced seniors are those experiencing marginalisation or are hard to reach, such as those who are: homeless or near homeless; living with a physical or mental disability; newcomers or English language learners; providing caregiving; lacking access to family and social supports; living with a low income or are financially challenged with limited disposable income, and have limited access to financial resources.

The results from this survey will be disseminated via report and virtual presentation to the Edmonton Hoarding Coalition (EHC) in January to February 2023 (tentative). If you wish to be invited to this virtual presentation or receive an email about the results of this survey, please let us know. We will request your contact information at the end of this survey. We will also be conducting interviews during the next phase of this project to better understand current approaches and best practices for supporting low-resourced seniors with hoarding behaviour to improve their housing situations. You will be invited to participate in a follow-up interview at the end of this survey.

Please note that your information is highly confidential, and we will ensure your privacy. We will aggregate and anonymize your information during our analysis to provide high-level insights. We may contact you to participate in the survey analysis dissemination or follow-up interviews only if you register your email.

You may withdraw your consent to participate in this study at any time.

If you have any questions or concerns about this survey or research project, please contact Nicole Smith (nsmith@mysage.ca), the Director of Research and Community Engagement with Sage Seniors Association.

This project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in our information, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Board, at:

Community Research Ethics Office (Canada) Corp.
c/o Centre for Community Based Research,
190 Westmount Road North, Waterloo ON N2L 3G5
Email: creo@communitybasedresearch.ca
Telephone: 1-888-411- 2736

Thank you for your participation!

PART I: ORGANIZATIONAL QUESTIONS

Q1 Which organization do you represent and what is your position?

- Organization
- Position

Q2 Which programs or services does your organization offer? (select all that apply)

- Cleaning, organizing, or decluttering
- Case management
- Referrals
- Therapy or other mental health services
- Education or training
- Group CBT
- Individual CBT
- Meals and food
- Housing
- Legal Services
- Filling Prescriptions
- In-home visits/assessments
- Other

Q3 In the context of hoarding, which area does your organization primarily operate?

- Health
- Mental Health
- Environmental Health and Safety
- Housing
- Senior-serving
- General Hoarding
- Municipal Task Force
- Provincial Task Force
- Other (please specify)

Q4 Does your organization have staff with the following designations? (select all that apply)

- Licensed therapist (Graduate-level education such as a master's or PhD)
- Non-licensed therapist
- Social worker
- Nurse (RN or LPN)
- Medical Doctor of Nurse Practitioner
- Professional Organizer
- Certified Facilitator
- Other roles that require specific degrees or designation (please specify)

PART II: CLIENT QUESTIONS

Please recall that our research focus is people aged 55+ with hoarding behaviour and keep this in mind while answering the following questions.

Q5 Approximately how many people aged 55+ (with or without hoarding behaviour) does your organization serve a year?

- Fewer than 50
- 51 – 100
- 101 – 200
- 201 – 500
- 501 – 1000
- 1001 – 2000
- 2001 – 5000
- More than 5000

Q6 Approximately what percentage of people aged 55+ that you serve exhibit hoarding behaviour?

- Sliding scale (0-50-100)

Q7 How do you identify participants who struggle with hoarding behaviour?

- Participants self-declare their condition
- Participants are assessed for hoarding behaviour
- Participants are referred by a friend or family member
- Participants are referred by another organization (please specify below)
- Other (please specify below)

Q8 How do you assess for hoarding behaviour?

- Open-ended

Q9 In general, participants who exhibit hoarding behaviour present or identify primarily as:

- Male
- Female
- Other

PART III: HOUSING INSECURITY

Housing insecurity can be defined as having difficulty managing, maintaining, or acquiring safe and appropriate housing. In the context of hoarding behaviour, housing insecurity can occur because of conflicts with landlords and other tenants, eviction, and homelessness. Hoarding behaviour may also affect a person's ability to maintain or acquire employment, which may affect their finances. Please keep these considerations in mind while answering the following questions.

Q10 Approximately what percentage of your participants with hoarding behaviour experience housing insecurity?

- Sliding Scale (0-50-100)

Q11 Can you elaborate on how you assess or determine housing insecurity?

- Open-ended

Q12 How does hoarding behaviour affect the housing security of your clients?

- Open-ended

Q13 What additional resources or services would help you support your clients in improving their housing security?

- Open-ended

PART IV: CONCLUSION

Thank you for taking the time to complete this survey, we appreciate your participation. This last section will ask for your contact information if you would like to receive the results of this survey and/or participate in an interview. The interviews will be conducted according to what is most convenient for you (e.g. phone, virtual, in-person). Your contact information will only be shared with members of the research team to facilitate these follow-up activities. You may withdraw consent to use or keep your contact information at any time.

Q14 Please select all that apply:

- I want to be invited to the virtual presentation of these survey results
- I want to receive a summary of these survey results by email
- I want to recommend a colleague for participation in this survey
- I want to participate in an interview for this research project
- I want to recommend a colleague for participation in an interview

Q15 If you selected any of the options above, please provide your contact information here.

APPENDIX III

Interview Guide

INTRODUCTION

We are conducting interviews to identify the systemic barriers faced by service providers in supporting low-resourced older adults and seniors with hoarding behaviours experiencing housing insecurity.

You have been invited to this interview because your knowledge can shed further insight to the objectives of our research project. Your participation is voluntary, and you may withdraw at any time. This interview will take approximately 60 minutes to complete. The results from this research project will be disseminated via report and virtual presentation to the Edmonton Hoarding Coalition (EHC) in June 2023 (tentative). If you wish to be invited to this virtual or presentation or receive an email on the results of this study, please let me know.

Please note that your information is highly confidential, and we will ensure your privacy. Your data will be stored securely on our private Microsoft Teams account, with only me, Nicole Smith, having access to it. Your data will be stored in Microsoft Teams indefinitely.

The interview will be recorded and transcribed to text to ensure that all the information is captured.

Recordings and transcriptions will be securely stored indefinitely in SharePoint. Analysis will be aggregated and anonymized to provide high-level findings. To ensure privacy and confidentiality, any identifying and contact information will be removed from the transcripts; interview participants will be assigned aliases and the alias key will be kept separate from the transcripts. We may contact you to participate in the dissemination of the results or follow-up interviews **only** if you register your email. Incomplete interviews will still be used in the analysis, where appropriate and relevant, unless your consent is withdrawn.

A reminder that you may withdraw your consent to participate in this study at any time.

Are you comfortable with having this interview recorded?

I will start the recording now, and we can begin.

PART I: INTERVENTIONS (Suggested time: 15 minutes)

Question 1: What kind of interventions does your organisation offer to help support clients with hoarding disorder? Which interventions do you think have been the most successful?

> **Question 1b:** Why do you think this intervention(s) has or has not been successful?
>
> **Question 1c:** How do you think these interventions improve housing security among your clients?

Question 2: Does your organisation have interventions specifically to address housing insecurity?

> **Question 2b:** Why do you think this intervention(s) has or has not been successful?
>
> **Question 2c:** How do you think these interventions improve housing security among your clients?

PART II: CASE MANAGEMENT (Suggested time: 30 minutes)

Question 1: Can you describe what case management style your organisation uses to support clients with hoarding behaviour? For example, does your organisation follow harm-reduction, housing first, or collaborative approaches?

Question 2: How successful has this approach been in helping clients manage their symptoms (e.g., do clients experience a reduction in the severity of their symptoms)? How has this approach helped increase housing insecurity among clients?

Question 3: How does your organisation approach case management? Is it a specific framework applied to every situation, or does it change on a case-by-case basis?

> **Question 3b:** How effective is your approach to case management? In which situations is your approach effective? In which situations is your approach not effective?
>
> **Question 3c:** How do you help clients who are difficult to support, don't improve, or are beyond the scope of your organisation's interventions? For example, are clients referred elsewhere? (If so, where?)

Question 4: What is the completion rate of your hoarding disorder program/intervention?

> **Question 4b:** How do you decide if a client has successfully completed the program?
>
> **Question 4c:** If a client does not successfully complete your program, how do you decide to close a case file?

Question 5: What are critical success factors for clients in completing your program/intervention? How do you quantify success, other than completing the program (e.g., reduced intensity of hoarding disorder through HOMES Scale, SI-R Scale)?

PART III: RESOURCES & CLIENT-SYSTEMS INTERFACE (Suggested time: 15 minutes)

Question 1: How is your organisation funded?

Question 2: Research has found that hoarding responses can be maximised when service providers work in tandem to address a client's issue from different angles. That is, a single organisation cannot realistically address every issue a client faces such as mental health, housing, food security, and employment. Do you coordinate with other organisations in delivering services? If so, who/how; if not, why??

Question 3: What system or structural barriers does your organisation face in delivering services? What systems-level changes do you think could improve how your organisation delivers services?

Question 4: It can be difficult for clients or their support system to find the resources that they need because of a lack of awareness, education, denial, or confusion. How could the system be improved to better support clients and their networks?

> **Question 4b:** How are clients referred to your organisation?