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## How Well Do Hoarding Research Samples Represent Cases That Rise to Community Attention?

**Sheila R. Woody<sup>1</sup>, Peter Lenkic<sup>1</sup>, Christiana Bratiotis<sup>2</sup>, Kate Kysow<sup>1</sup>, May Luu<sup>1</sup>, Jesse Edsell-Vetter<sup>3</sup>, Randy O. Frost<sup>4</sup>, Nathanael Lauster<sup>5</sup>, Gail Steketee<sup>6</sup>, David F. Tolin<sup>7</sup>**

<sup>1</sup>Department of Psychology, University of British Columbia, Vancouver, Canada

<sup>2</sup>School of Social Work, University of British Columbia, Vancouver, Canada

<sup>3</sup>Metro Housing Boston, Boston, MA, USA

<sup>4</sup>Department of Psychology, Smith College, Northampton, MA, USA

<sup>5</sup>Department of Sociology, University of British Columbia, Vancouver, Canada

<sup>6</sup>School of Social Work, Boston University, Boston, MA, USA

<sup>7</sup>Institute of Living, Hartford, Connecticut and Department of Psychiatry, Yale University, CT, USA

### Abstract

This study used archival data from three different research groups and case file data from three independent community organizations to explore how well research samples reflect cases of hoarding that come to community attention. Using data from 824 individuals with hoarding, we found that research volunteers differ from community clients in several ways: community clients are older, more likely to be male and less likely to be partnered; they have lower socio-economic status and are less likely to demonstrate good or fair insight regarding hoarding severity and consequences. The homes of community clients had greater clutter volume and were more likely to have problematic conditions in the home, including squalor and fire hazards or fire safety concerns. Clutter volume was a strong predictor of these conditions in the home, but demographic variables were not. Even after accounting for the influence of clutter volume, the homes of

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Correspondence concerning this article should be addressed to Sheila Woody, Department of Psychology, University of British Columbia, Vancouver, BC V6T 1Z4 Canada. sheila.woody\_at\_ubc.ca.

**Sheila R. Woody:** Conceptualization, Methodology, Investigation, Writing – Original Draft, Supervision, Project administration, Funding acquisition

**Peter Lenkic:** Conceptualization, Formal analysis, Data curation, Writing – Original Draft, Visualization

**Christiana Bratiotis:** Conceptualization, Writing – Review & Editing

**Kate Kysow:** Writing – Original Draft

**May Luu:** Conceptualization, Writing – Original Draft

**Jesse Edsell-Vetter:** Investigation

**Randy O. Frost:** Investigation

**Nathanael Lauster:** Conceptualization

**Gail Steketee:** Investigation, Writing – Review & Editing

**David F. Tolin:** Investigation

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community-based clients were more likely to have squalor. These findings suggest limitations on the generalizability of research samples to hoarding as it is encountered by community agencies.

### Keywords

hoarding; sampling (experimental); biased sampling; community mental health

Characterized by considerable difficulty discarding ordinary items and corresponding large quantities of clutter, hoarding prevents the ordinary use of living spaces in the home, causing significant distress and impairing everyday functioning (American Psychiatric Association, 2013). Diagnosis of the condition requires establishment of the individual's intention to save the items that have accumulated in the home, or strong distress associated with discarding. Epidemiological studies suggest that the population prevalence of hoarding is 1.7% - 3.6% (Postlethwaite, Kellett, & Mataix-Cols, 2019). On average, hoarding symptoms begin during the teen years (Zaboski II et al., 2019), although help seeking, when it occurs, is delayed until the middle adult years (Frost, Steketee, Williams, & Warren, 2000). Comorbidity is common, especially major depression, other anxiety-based disorders, attention-deficit/hyperactivity disorder, and acquisition-related impulse control disorders (Frost, Steketee, & Tolin, 2011). Hoarding clients are also more likely than the general population to report a broad range of chronic and serious medical concerns, such as autoimmune diseases, obesity, rheumatism, stroke, or diabetes (Tolin, Frost, Steketee, Gray, & Fitch, 2008). Insight can be quite poor, and even good insight is likely to fluctuate (Tolin, Fitch, Frost, & Steketee, 2010).

Overall, hoarding is associated with broad impairment across multiple domains of functioning, including family and home management as well as leisure activities and work (Diefenbach, DiMauro, Frost, Steketee, & Tolin, 2013; Tolin et al., 2008). High clutter volume often interferes with the ordinary use of functional aspects of the home, such as preparing food, socializing, or finding important things. Hoarding clients often describe interpersonal problems and strained or broken family relationships (Grisham, Steketee, & Frost, 2008; Park, Lewin, & Storch, 2014). Those with hoarding disorder are more likely to live alone (Ayers, Saxena, Golshan, & Wetherell, 2010; Landau et al., 2011) and are less likely to have friends or family visiting the home (Diefenbach et al., 2013). Conflicts regarding the clutter are also likely to occur with housing providers, social services agencies, and neighbours.

Much of what we know about hoarding comes from samples of individuals who volunteer for university-based research, but hoarding also comes to light in community settings. In addition to the functional interference described above, hoarding can also pose a social problem that brings attention from community agencies that work in the areas of housing, fire prevention, and public health (Bratiotis, Sorrentino Schmalisch, & Steketee, 2011). Many cases of hoarding remain private until the situation becomes extreme, at which point multiple human service professionals become involved (Bratiotis & Woody, 2014; Frost, Steketee, & Williams, 2000). Fire hazards (i.e., physical conditions that could start or accelerate a fire), fire safety concerns (i.e., threats to safe evacuation of occupants or

first responders in the event of a fire), presence of mould, pest infestations, and excessive filth (squalor) are some of the conditions for which community agencies have clear legal and regulatory mandates for intervention (McGuire, Kaercher, Park, & Storch, 2013). In community studies of hoarding, squalor is relatively common, often associated with higher clutter volume or impaired access to bathroom or kitchen facilities (Luu, Lauster, Bratitotis, Edsell-Vetter, & Woody, 2018). One study showed that approximately one in every four or five residents who are having problems maintaining their housing endorse high levels of hoarding symptoms (Rodriguez et al., 2012).

Obvious differences between university-based research samples and community-referred clients raise questions about whether these two groups might differ in some key ways, including demographic characteristics and severity of conditions in the home. Due to their community service and regulatory mandate, community agencies likely encounter a more diverse range of people who hoard than are represented by research volunteers. Certainly, previous research has shown that the demographics of research participants may not match the broader population to which the research aims to generalize, although this has not been established in hoarding. For example, population prevalence estimates for hoarding do not differ by gender (Postlethwaite et al., 2019), but women appear to volunteer for research in greater numbers (e.g., Frost, Steketee, Tolin, Sinopoli, & Ruby, 2015; Tolin, Frost, Steketee, & Muroff, 2015). Research on other aspects of psychopathology also suggests the importance of examining racial differences (Cha, Erar, Niaura, & Graham, 2016; McClure et al., 2017). Differences in socioeconomic status might also be expected, as volunteers in randomized controlled trials for substance use disorders are better educated and more likely to be fully employed than the broader target population (McClure et al., 2017; Susukida, Crum, Stuart, Ebnesajjad, & Mojtabei, 2016); this may occur in hoarding as well. Given the special concerns related to hoarding among older adults, age differences are also important to examine (Ayers, Scheiuser, Liu, & Wetherell, 2012; Cath, Nizar, Boomsma, & Mathews, 2017; Dong, Simon, Mosqueda, & Evans, 2012; Steketee, Frost, & Kim, 2001).

An important differentiation between recruitment for university research and identification of cases for community intervention is that community hoarding clients do not typically self-refer. Generally, research participants must be able to identify their own hoarding problems and be willing to volunteer for research on the topic. Poor insight about the extent or consequences of the hoarding behaviour is an obvious barrier to volunteering for research. Most community hoarding clients are not seeking help, and many actively resist intervention (Tompkins, 2015). Many also fear the consequences of discovery of their hoarding behaviour, which can range from social (e.g., stigma, ostracism, judgment) to deeply practical. For example, in an online study, Tolin and colleagues (2008) reported that up to 12% of hoarding participants had been evicted or threatened with eviction due to hoarding.

Community-based interventions often involve marginalized and vulnerable clients, such as people living on a low income, older adults, or those in poor physical health (Bratitotis et al., 2011; Tompkins, 2015). Generally speaking, agencies must serve all referred clients who fit their mandate (e.g., to ensure safety of community-dwelling older adults, to preserve tenancy for those at risk of homelessness). Treatment studies, in contrast, often exclude

clients with complicating factors such as co-occurring serious mental illness, substance use disorders, cognitive impairment, or active suicidal ideation (e.g., Ayers et al., 2018; Steketee, Frost, Tolin, Rasmussen, & Brown, 2010; Tolin et al., 2019). Although front-line community professionals are well positioned to provide information about these “hidden” clients and their context, community agencies rarely collect, and almost never publish, data about their clients, conditions of the homes or related problems. This situation highlights an important gap in knowledge about hoarding and a missed opportunity. For an example of this type of research, see Snowdon and Halliday (2011), who used community agency data to report degree of squalor (i.e., filthy and unhygienic conditions) in hoarded homes.

Accordingly, we were interested in the degree to which community clients and research participants might differ in the severity of their hoarding behaviour and the consequences for their living conditions. Although data from community agencies are often collected less systematically than researcher-collected data, one important strength is an independent assessment by trained and objective assessors who visit the home and converse with the individual engaged in hoarding as well as, in many cases, collateral informants such as family members, neighbours, or housing providers. The assessor may be a housing inspector, a mental health professional, or a fire inspector, to name a few of the disciplines involved (Bratiotis, Sorrentino Schmalisch, & Steketee, 2011). The mandate of each agency influences which aspects of the hoarding problem they assess, but frequent areas of assessment include basic living standards and health/safety concerns such as cleanliness, the functioning of utilities, access and mobility within the home, and housing stability (e.g., risk of eviction). Self-report measures are rarely used.

This paper utilizes data from published research studies as well as community-referred samples to explore differences between research samples and hoarding that occurs in the community at large. We examined demographic profile, clutter volume, and conditions in the home.

## Method

### Data Sources

This study used archival data from three different research labs and case file data from community agencies in three cities. The research data were collected in university-based studies of the psychopathology of hoarding; each study had institutional ethical review prior to data collection. The community data were collected by agencies offering specialized programs to assist residents with hoarding-related problems. These agencies, representing both governmental and non-governmental organizations, varied in the mandates for their work. Each agency conducted in-home assessments to inform an intervention plan and to broker relevant referrals to community-based services.

### Research samples.

Frost, Steketee, and Tolin (2011) collected data from 217 adults with hoarding disorder who were recruited in New England via referral from clinical settings, advertisements, and media appearances. Diagnoses were based on the Hoarding Rating Scale Interview (HRS-I)

conducted by trained clinicians. Exclusion criteria were current suicidal ideation, psychotic symptoms, substance use disorder or significant cognitive impairment. The mean total score on the Saving Inventory-Revised (SI-R) for participants in this study was 61.7 ( $SD = 13.6$ ).

The Tolin et al. (2012) sample of 46 adults with hoarding disorder was recruited using advertisements placed in a Hartford, Connecticut clinic specializing in treatment for hoarding. Hoarding was diagnosed using the HRS-I conducted by trained postdoctoral fellows or postgraduate research assistants. Photographs of living spaces or home visits were used to clarify the severity of hoarding symptoms when questions arose. Exclusion criteria were current serious suicidal ideation or history of psychotic, neurological, or substance use disorders, in addition to factors that would contraindicate fMRI (e.g., pregnancy). The mean SI-R total score for participants in this study was 63.6 ( $SD = 12.6$ ).

For the final research sample, Woody and her colleagues (2019) collected a sample of 74 adults who were recruited in the Vancouver area through community advertisements and a registry of previous participants in hoarding research. Trained and supervised graduate students assigned diagnoses based on the MINI International Neuropsychiatric Interview (with a specialized hoarding module created for research use) in conjunction with photographs of living areas of the participant's home. Interviewers made a judgment of the participant's insight following the structured interview and inspection of the photographs. Exclusion criteria were neurological conditions or current substance use disorders. The mean SI-R total score for participants in this study was 54.9 ( $SD = 13.4$ ).

We will refer to these research samples as Frost, Tolin, and Woody, respectively, after their principal investigators.

### **Community-referred samples.**

Three community agencies completed in-home assessments that involved establishing rapport, interviewing the resident, and conducting a visual inspection of the home. One program also administered a brief self-report questionnaire (see below). Researcher involvement in the data collection process varied across agencies but was generally minimal. More detail about these three agencies can be found in Luu et al. (2018).

The Hoarding Action Response Team (HART) is a collaboration between health service and building code enforcement officials located in Vancouver, British Columbia. HART's mandate is to intervene in hoarding cases to maintain safety for the resident and neighbours, while striving to avoid prosecution (e.g., for fire code infractions) and eviction. Data were collected for this study in two phases, from February 2011 to January 2015 ( $N = 140$ ) by a team of two healthcare workers, a fire inspector, and a property use inspector, and from March 2015 to April 2017 ( $N = 117$ ) by a team of one psychiatric nurse and a fire inspector. As the data collection procedures differed between the two phases, we will refer to the samples as Vancouver 1 and Vancouver 2, respectively. As a research consultant to the HART team, the senior author and her research colleagues advised on multi-disciplinary assessment targets and tools, entered data from paper forms, and cleaned and organized data from electronic sources. Researchers also monitored incoming data to help the community team reduce missing data. Institutional ethical approval was obtained prior to collecting data.

The Metropolitan Boston Housing Partnership (MBHP; now called Metro Housing Boston) was a housing advocacy organization based in Boston, Massachusetts that aimed to preserve tenancy for those living in affordable or subsidized housing. Data for this study were collected from June 2011 to June 2014 ( $N = 139$ ) as part of MBHP's Hoarding Intervention and Tenancy Preservation Project (Davis & Edsell-Vetter, 2015). A highly experienced case manager collected all data as part of the housing assessment and long-term engagement with clients, supported in part by an agency grant from the Oak Foundation. Researchers at Boston University provided MBHP with data collection recommendations and grant-writing assistance. MBHP independently implemented the project and collected and managed the data, sharing the de-identified data with researchers once it was complete. We will refer to this community data set as Boston.

The Gatekeepers Program run by Catholic Family Services in Hamilton, Ontario serves community-dwelling older adults who are at risk for self-neglect. The program aims to prevent eviction, homelessness, and unnecessary hospitalizations, as well as to promote overall health, wellbeing, and safety in the home. Prospective clients are referred by members of the community, thanks in part to the program's extensive outreach efforts teaching community members to recognize signs of self-neglect among older adults. Case managers and community support workers with specialized training collected the present case file data from April 2010 to February 2014 ( $N = 129$ ) as part of their initial evaluation. Only cases with hoarding problems were included in the present analysis. We will refer to this community data set as Hamilton.

Unlike the Vancouver and Boston groups, Hamilton's data collection procedures were developed with no researcher input. This organization, due to the nature of its work, was accustomed to conducting in-home assessments and charting their work in a sophisticated electronic records system. Our research team formed a community partnership with this program, which provided access to de-identified data for research purposes. The senior author obtained university ethical approval in advance for secondary data analysis of de-identified data from both Boston and Hamilton.

Across these community samples ( $N = 465$ ), the average self-referral rate was 8.0% (range 5.7% to 9.2%), with no significant differences across samples,  $\chi^2(3, N = 465) = 1.2, p = .75$ . Boston referrals came primarily from the Tenancy Preservation Project (clients who were referred due to threat of loss of housing subsidy as a result of hoarding behaviour). As described above, Hamilton referrals were identified by members of the community who encountered older residents on a regular basis (e.g., postal workers, meal delivery personnel). The majority of Vancouver referrals came from housing providers, neighbours, or friends. About a third came from health or social services providers, including first responders.

## Measures

Due to the diversity of data sources within and across the community and research samples, not all constructs of interest were available at every site; all available data were used for each analysis. Importantly, like most community agencies serving hoarding clients, those contributing data to this report did not make formal hoarding disorder diagnoses.

### Hoarding severity.

The Saving Inventory - Revised (SI-R; Frost, Steketee, & Grisham, 2004) is a 23-item self-report measure of the major features of hoarding (acquisition, difficulty discarding, and clutter) that has shown good reliability and validity in previous research. All three research samples in the present study used this measure; the total score mean and standard deviation are presented with the description of the research samples. Internal consistency (full sample and separately by research sample) was 0.91 for the total score.

### Clutter volume.

The Clutter Image Rating (CIR; Frost, Steketee, Tolin, & Renaud, 2008) is a widely-used measure of clutter volume that includes nine photographs each of a kitchen, living room, and bedroom with progressively higher levels of clutter. The rater chooses the photo, numbered from 1 (none) to 9 (extreme), that most closely resembles the clutter volume in each room. Vancouver 2 provided a single global assessment of clutter volume over the entire home, whereas Boston and the research samples (Frost, Tolin, and Woody) recorded a rating for each room. To facilitate comparisons across samples, an average of the kitchen, living room, and bedroom ratings was calculated for those samples that assessed multiple rooms. The CIR was self-reported for Tolin's sample, whereas the assessor/experimenter made CIR ratings for Vancouver 2 (on the basis of a home visit) and Woody (based on photographs of the home). For Frost's sample, assessor ratings from a home visit were used when available (73% of participants); otherwise the participant's ratings were used.

### Functional impairment.

Developed by the Massachusetts Statewide Steering Committee on Hoarding, the *HOMES Multidisciplinary Hoarding Risk Assessment* (Bratiotis et al., 2011) identifies areas of risk in hoarded homes during brief initial assessments. Assessors from both Boston and Vancouver 1 completed this measure. Multidisciplinary community agencies use this checklist to help prioritize problem areas and formulate remediation plans. Items include household conditions relevant to health (e.g., cannot use bathtub/shower, garbage overflow, presence of pests), obstacles to safe movement in the home (e.g., unstable piles/avalanche risk), and structural safety (e.g., caving walls). For the present study, insight was coded as poor if the assessor checked *either* the item indicating confused mental state (i.e., "unaware, not alert, or confused") *or* the item indicating the client's lack of understanding of the seriousness of the situation.

The *Activities of Daily Living – Hoarding* (ADL-H) scale assesses impairment in various daily activities on scales from 1 (*can do it easily/no problem/not at all an issue*) to 5 (*unable to do it/severe problem*). Woody's group used a 15-item version that focuses on daily activities, such as ability to prepare food, use the bathroom sink, or find important things. Both the Frost and Tolin groups used an expanded 29-item version that additionally assessed living conditions such as structural damage, presence of rotting food, or non-functioning utilities and safety issues such as fire hazards or blocked exits. The experimenter completed this measure for Frost's study, whereas participant ratings were used in both the Tolin and Woody studies.

Although Hamilton did not use the ADL-H per se, they evaluated similar constructs using a structured assessment tool. Case workers made ratings of home functionality (e.g., access to functioning kitchen appliances, bathroom fixtures, and plumbing, heat, and electricity), presence of squalor (i.e., spoiled food, pests, mould, urine/feces), obstacles (e.g., blocked exits or stairways, ease of mobility within the home, ability to answer the door), and fire-related concerns (e.g., fire hazards, functioning smoke detectors, blocked egress). Most items were assessed using a *Yes/No* format. Exceptions were problems with squalor, which were assessed on a 3-point scale (1 = *little or none*, 2 = *moderate*, 3 = *severe*), and level of insight, which was assessed as *none*, *mild*, *moderate*, and *fully aware*.

### Data Analytic Approach

As clutter volume and impairment are of primary interest in the present study, participants were excluded if they had missing data for *both* clutter volume and impairment. The final sample for analysis thus consisted of 824 individuals with hoarding for which either clutter volume or impairment data were available (Frost  $N=217$ , Tolin  $N=46$ , Woody  $N=74$ , Boston  $N=132$ , Hamilton  $N=108$ , Vancouver 1  $N=138$ , Vancouver 2  $N=109$ ). The proportion of cases that were excluded on this basis ranged from 0 to 5% for all samples except Vancouver 2 (6.8%) and Hamilton (16.3%). There was no discernible pattern for the Vancouver 2 missing data. Missingness for the Hamilton data was predicted by Staff ID; two staff members failed to record impairment data across all clients they assessed. The reason for this omission is unclear, though as a result, the cases that were retained for the present study were significantly older than were those who were excluded due to missing data (retained  $M_{age}=71.0$  years,  $SD=8.5$ ; excluded  $M_{age}=64.6$ ,  $SD=9.6$ ),  $F(1, 120)=8.2$ ,  $p=0.005$ ,  $\eta^2=0.06$ . Participants who were excluded due to missing data did not differ in terms of gender frequency, insight, relationship status, income, or self-referral ( $p$  values  $>.13$ ). When interpreting the results, the possibility of bias in the parameter estimates for the Hamilton sample must be considered due to the non-random missing data.

To facilitate comparisons across samples of impairment and conditions in the home, we formed categories of impairment comprised of items from both the ADL-H and the HOMES. Table 1 shows the categories and the items included in each category for subsequent data analysis. A participant's functioning was classified as "impaired" in a given category if there was a positive finding on any item within the category. To take an example, "impairment" was coded for utilities if the home showed problems with water, heating, or electricity. For items assessed with the ADL-H, which uses a 5-point scale, impairment was classified as a rating of at least 3 (moderate impairment), following the strategy of Ayers, Scheuier, Liu, and Wetherell (2012). For Hamilton squalor items, impairment was defined as a rating of at least 2 (moderate). For the Hamilton insight item, impairment was defined as insight assessed as *none* or *mild* to put it on the same dichotomous scale as the Boston and Vancouver 1 insight data.

To account for the hierarchical nature of the data (individuals nested within samples), differences between sample type (community vs. research) in demographic characteristics, clutter volume, and functional impairment were evaluated using linear mixed-effect regression for continuous variables and logistic mixed-effect regression for binary



categorical variables. Sample type (research vs. community) was modeled as a fixed effect, and the individual participant within sample as a nested random effect. To further evaluate the effects of sample type on impairment, we used hierarchical logistic mixed effect regression with demographic variables included in the first step, clutter volume in the second step, and sample type in the third step, with individual within sample as the random effect for each step. Chi-square likelihood ratio tests were used to evaluate the significance of parameters in all of these models. All tests were evaluated for significance at the  $p = .05$  level.

## Results

### Participant Characteristics

As shown in Table 2, which presents an overview of the characteristics of the final sample of 824 individuals, demographic characteristics differed across community and research samples. Likelihood ratio tests from linear and generalized linear mixed-effect models revealed that, compared with research samples, clients in the community samples were significantly older, more likely to be male and less likely to be partnered. The age difference persisted even when excluding the Hamilton sample, which was drawn from an agency whose mandate specifically targeted older adults (without Hamilton: community  $M = 62.4$ ,  $SD = 13.5$ ; research  $M = 52.0$ ,  $SD = 10.6$ ,  $\chi^2(1) = 11.8$ ,  $p < .001$ ,  $\beta = 0.86$  [0.38, 1.33]). As Table 2 shows, community clients had lower socio-economic status, in that they were less likely to be employed or to have attended at least some college, and were more likely to be living on an annual income below \$20,000. Community clients were also more likely to be rated by assessors as having poor insight into the severity or consequences of their hoarding behaviour. There was no significant difference in proportion of participants who were characterized as non-White, although the CI was very wide for this comparison, likely reflecting differences in the background communities (e.g., Vancouver has a higher non-White population than does Boston, and the non-White populations are very different in those two cities).

### Conditions of the Home

Table 3 shows CIR ratings and areas of functional impairment across data sources. As shown in the right-most columns of Table 3, community samples had significantly higher clutter volume than research samples. In comparison with research participants, the homes of community-referred clients were more likely to have squalor, fire hazards and fire safety concerns. The analysis also suggested that community-referred clients were more likely to have problems with mobility within the home, although this result had a  $p$  value of .06. On the other hand, the results showed no significant differences between research and community samples in the use of the kitchen or bathroom, structural problems in the home or functioning utilities. (See Table 3.) Notably, the frequency of problems with utilities (i.e., water, plumbing, heat, electricity) was fairly low in both research and community samples, making it difficult to interpret the results of that analysis.

Given the significant differences between research and community samples in clutter volume and client characteristics, we examined whether either variable accounted for differences

in impairment. We conducted four hierarchical mixed-effect logistic regression analyses to evaluate the effects of demographic characteristics, clutter volume, and sample type (research vs. community) on the outcomes of squalor, fire hazards, and fire safety issues (i.e., those variables for which significant differences between community and research samples were observed); we also analyzed the outcome of mobility, which just missed the traditional  $p < .05$  level of significance. Predictors in the first step in the hierarchical models were demographic characteristics (age, gender, relationship status, employment status, income level, and education level); the second step included clutter volume, and the third step added sample type (research vs. community sample). A random effect of individual within sample was entered for each of these models. Data in Table 4 include only the Frost and Tolin research samples and the Boston community sample because the other samples were lacking key variables for this analysis.

No demographic variable appeared as a significant predictor of squalor, fire hazards, fire safety, or mobility. Clutter volume, on the other hand, was a significant predictor of all four. For every additional point in CIR (holding all demographic and sample type variables constant), the odds of functional impairment were approximately doubled. After accounting for both CIR and demographic differences, community and research samples were no longer significantly different in frequency of fire hazards, fire safety concerns, or mobility. However, clients in the community sample were five times more likely to experience squalor, holding all other predictors constant. Although only the Boston community data were included in this analysis, Table 3 shows that the frequency of squalor was comparable for the other community samples.

## Discussion

The purpose of the present study was to evaluate whether research samples of hoarding disorder differ from cases that come to the attention of community agencies. Using data from three independent community agencies and three research groups, we found several important differences. Research volunteers are younger and more likely to be female and partnered. They are more likely to show good or fair insight about the severity and consequences of hoarding behaviour. Research participants are also higher in socio-economic status in terms of education, employment and income. The homes of research participants have lower levels of clutter volume and are, accordingly, less likely to show (a) squalor, (b) conditions that could ignite or accelerate a fire (fire hazards), and (c) impediments to safe evacuation in the event of a fire (fire safety concerns), a pattern that probably also holds true for (d) impaired mobility within the home. Clutter volume was the main predictor of these problems in the home and accounted for the sample differences in fire hazards and fire safety. Even after accounting for clutter volume, however, community samples were still more likely to involve squalor – an important topic for further study.

On average, clients in community samples scored 1.5 points higher on the CIR than did participants in research, 95% CI [0.21, 2.80]. Differences in clutter volume are likely due to selection bias for community agencies, as higher clutter volume is more likely to trigger a complaint or referral to community services. Considering the differences in income and education level, it is also possible that research volunteers have larger homes, which

is relevant for how cluttered a home would become given a set volume of possessions. Whereas about a third of the Vancouver 1 (31%) and Hamilton (35%) samples lived in a detached single-family home, nearly half of the Frost (48%) participants did. Of course, the base rate for living in this type of housing likely differs in these different communities.

It is important to note that clutter volume accounts for only one facet of the complex problem of hoarding. Community agencies did not collect formal data on psychological facets of hoarding, such as emotional difficulty with discarding or excessive acquisition behaviour, so we were unable to evaluate the possibility that hoarding symptoms in general were less severe in research samples. This raises a broader limitation of the current study, in that we were unable to examine all constructs of interest across all sites due to differences in data that were collected. Most importantly, assessment of most constructs involved different measures across sites, and of course the assessors themselves differed across sites in both their personal identity and their disciplinary training, and no inter-rater reliability data are available. As a result, it is possible that the observed differences are due to methodological factors rather than differences between community and research samples.

On the other hand, a relatively consistent picture emerges across these diverse settings, assessors, and measures, suggesting that community samples represent a different (and less privileged) demographic and more severe problems related to hoarding behaviour. These differences can be understood, we believe, from the differences between research recruitment and community agency case-finding strategies. Research recruitment is biased toward individuals who feel comfortable coming to a university or hospital setting, who have enough insight into their hoarding to label the problem appropriately, and whose housing situation is not precarious enough to represent a clear threat of discovery. Community agencies receive referrals that are biased toward individuals who are vulnerable in some way (e.g., for eviction, frail older adult, cognitively impaired) and toward more severe cases that require intervention even if the resident does not seek help. Overall, these data suggest that university-based researchers are sampling from a different segment of the hoarding population than is served by community agencies. Obviously, interventions that are demonstrated to be efficacious in university-based studies may have limitations when applied to segments of the population that are hidden from researchers. Studies of community-based interventions for severe hoarding problems are greatly needed.

A common stereotype is that people who are lower in socioeconomic status keep less attractive homes in the sense of volume and arrangement of clutter as well as cleanliness. Our analysis found no evidence that demographic characteristics accounted for sample differences in conditions in the home; socioeconomic status represented by employment, income, and education was not predictive. Importantly, sample differences in race or ethnicity were not well tested in this study because Canadian sites do not collect these data. Our clinical and community experience suggests, however, the possibility of important cultural differences in norms and standards for the volume and arrangement of possessions in the home. Although this topic has been neglected in research, it may be important for clinicians and front-line community workers to consider when working with clients.

Several other potentially important individual differences factors are not represented in this study due to lack of research sample data for comparison: eviction risk, medical complexity, and social isolation. Substantial portions of our community samples were at clear risk of eviction due to hoarding behaviour, ranging from 31% in the Vancouver 1 sample to 45% in the Boston sample. No data were available for eviction risk in the research samples, although in Frost's sample, 22% of individuals reported having "house/landlord issues", which could include eviction risk as well as landlord-tenant conflict. In our experience with community samples, medical complexity often seems to be relevant to hoarding behaviour, for example by making it more difficult for the client to reduce clutter in the home. We have also observed that hoarded conditions can interfere with delivery of necessary home-based medical care, sometimes preventing release from hospital. In the Hamilton context, 17% of clients self-reported severe impairment in daily activities due to medical needs. In the Vancouver 1 sample, 14% of clients were referred to other services for treatment of health problems. Finally, social isolation was not well assessed in these datasets, but it is likely relevant to hoarding in multidirectional ways. In the Boston data, 32% of clients reporting having no friends or family inside or outside the home. Of the Hamilton clients, 12% rated their "feelings of connectedness" as being *not so good* or *very poor*. Among the Frost hoarding research participants, 17% reported that no one else visits their home. Current CBT approaches to hoarding disorder neglect the issues of eviction, medical complexity, and social isolation; more research on the importance of these challenges will provide a foundation for targeted interventions to address them.

Recruitment strategies for research and community samples differed markedly. The research samples included in this study used recruitment strategies that are typical of psychopathology research: public advertisements and clinical referrals. In contrast, the community agencies used case-finding strategies that were consistent with their unique service mandates. For example, the Boston agency specifically targeted individuals who were at risk of losing their housing, of whom just 11% were in market-priced rentals. Only 14% of the Boston participants owned their home, compared to 36% and 49% in the Hamilton and Vancouver 1 samples, respectively.

The Hamilton data are from a community agency that specifically aims to locate and serve community-dwelling older adults who are at risk for self-neglect. Consistent with this mandate, the clients, with a mean age of 71 years ( $SD = 8.5$ ), were significantly older than those in the other samples. Although age was not a significant predictor of functional impairment in the home, the Hamilton sample stands out in Table 3 as showing more impairment among the community samples, especially for kitchen, bathroom, structural, and fire safety problems. The Hamilton sample is comparable to the Ayers et al. (2012) small sample of older adults with hoarding. Statistically, the Hamilton sample had a significantly higher frequency of problems with food preparation, but no other ADL-H item had an odds ratio for which the 95% CI excluded 1.0. (See Supplementary Material for this analysis.) Taking together the vulnerability of older adults and the frequency of worrisome issues in the home in both the Hamilton and Ayers et al. samples, more study of older adults with hoarding is an important research agenda.

Those who lack insight into the problems caused by their hoarding are unlikely to volunteer for research. Poor insight into the severity or consequences of hoarding behaviour also is likely to interfere with the quality of self-report data. Furthermore, insight may represent a buffer against the development of some types of poor conditions in the home (Luu et al., 2018). Although we had insight data for only one research sample (Woody), that sample showed a higher frequency of good/fair insight than was observed in the community samples. Poor insight is difficult to assess with confidence unless the rater can compare observed conditions in the home with what the participant states about the home. The Woody assessments were assisted with photographs of the home that participants brought to the lab, but community agencies visit the home and get a much better sense of the client's level of insight and what factors influence fluctuations in insight. Because of the importance of insight for psychopathology and intervention research, better tools for assessing insight would be valuable for both clinicians and communities.

The idea that research volunteers differ along many dimensions from the broader population is not new. As Rosenthal and Rosnow (2009) carefully explored, research in the 1960s and 1970s clearly established gender differences in research volunteering, such that women are more likely to volunteer for research on most topics, but men more frequently volunteer for physically or psychologically stressful research (e.g., questions about sexual behaviour, methods requiring tolerance of pain). Compared to non-volunteers, research volunteers are more sociable and have higher need for achievement and approval motivation. Research volunteers typically have higher socio-economic status, especially higher educational attainment, than those who do not volunteer to participate in psychology research (Rosenthal & Rosnow, 2009). More recently, social psychologists have articulated the degree to which typical research samples, who tend to be recruited from the neighbouring areas surrounding research universities, differ from the broader global population at the expense of generalizability of research findings (Henrich, Heine, & Norenzayan, 2010). Although few researchers have examined this issue in psychopathology research, Kline et al. (2019) found that first-episode psychosis research participants had better social and role functioning and better neurocognitive performance than individuals from a clinic sample. The present results echo these earlier findings and indicate their relevance to hoarding.

Solutions to the problem of representativeness in research samples are beginning to appear. In the area of addictions research, respondent-driven sampling has been developed to locate "hidden populations" of hard drug users (Oteo Pérez, Benschop, & Korf, 2012). Woodall, Morgan, Sloan, and Howard (2010) identified several potentially solvable barriers to participation in mental health research, including transportation difficulties, distrust or suspicion of researchers, language barriers, physical illnesses, and stigma attached to mental illness. Research on community samples is not without its challenges, including ethical issues of privacy and consent, time constraints of community workers, reliability and validity of observational measures, and standardization of assessment procedures, to name a few. Nevertheless, in the context of hoarding, building community-university partnerships may improve representativeness and expand the generalizability of research on hoarding psychopathology and treatment as well as improve translation of research findings to the wide range of practice of interventions for hoarding.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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### Highlights

- Research volunteers differ from cases of hoarding that come to community attention
- Community hoarding cases have a different demographic profile from research samples
- Conditions in the home are less severe for research volunteers
- Clutter volume predicts a range of problematic conditions in the home

**Table 1.**

Items Used to Classify Functional Impairment Across Samples

Measure	Research Samples			Community Samples	
	Frost and Tolin (ADL-H 29 items)	Woody (ADL-H 15 items)	Boston and Vancouver 1 (HOMES)	Hamilton (structured intake)	
<b>Use of Home</b>					
<b>Mobility</b>	Mobility, answer door, EMT, stairs	Mobility, answer door	Move freely/safely, EMT	Mobility, answer door, EMT, stairs	
<b>Kitchen</b>	Fridge, stove, sink, prep food	Fridge, stove, sink, prep food	Stove/fridge/sink, prep food	Fridge, stove, sink, prep food	
<b>Bathroom</b>	Toilet, sink, bath/shower	Toilet, sink, bath/shower	Toilet, bath/shower	Toilet, bath/shower, sink	
<b>Living Conditions</b>					
<b>Structural</b>	Structural damage	-	Roof, walls, unstable floorboards/stairs/porch	Structural damage	
<b>Utilities</b>	Water, heat	-	Plumbing, heat/electricity	Hot water, heat, electricity	
<b>Squalor</b>	Rotten food, insects, urine/feces	-	Spoiled food, pests, urine/feces, mould, garbage overflow	Rotten food, pest infestation, urine/feces, mould	
<b>Fire Concerns</b>					
<b>Fire Hazards</b>	Fire hazards	-	Flammable items, blocked/unsafe heater, hazardous materials, exposed wires	Fire hazards	
<b>Fire Safety</b>	Exit quickly, exits blocked	Exit quickly	Exits/vents blocked	Exit home, exits blocked, smoke detectors	

Note: EMT = emergency medical technician access. Vancouver 2 did not formally assess these domains in the home. ADL-H = Activities of Daily Living – Hoarding. Fire hazards are conditions that could start or accelerate a fire. Fire safety refers to threats to safe evacuation of occupants or first responders in the event of a fire.

**Table 2.**

Participant Characteristics for Each Sample

Measure	Research Samples				Community Samples			Comparison: Research vs. Community		
	Frost N = 217	Tolin N = 46	Woody N = 74	Boston N = 132	Hamilton N = 108	Vancouver 1 N = 138	Vancouver 2 N = 109	Research N = 337	Community N = 487	
Age	52.6 (10.3)	50.5 (8.9)	51.2 (12.3)	56.9 (12.8)	71.0 (8.5)	63.9 (13.1)	67.7 (12.2)	52.0 (10.6)	64.4 (13.0)	$\chi^2 = 13.2, p < .001$ $b = 13.34, [6.33, 20.36]$
Male Gender	50 (23%)	12 (26%)	16 (22%)	53 (40%)	44 (42%)	71 (54%)	47 (44%)	78 (23%)	215 (45%)	$\chi^2 = 36.6, p < .001$ OR = 2.71, [1.87, 3.91]
Not Partnered	126 (61%)	31 (67%)	-	120 (94%)	93 (89%)	-	-	157 (62%)	213 (92%)	$\chi^2 = 50.0, p < .001$ OR = 6.85, [3.70, 11.90]
Not Employed	102 (50%)	20 (43%)	18 (24%)	117 (89%)	-	-	-	140 (43%)	117 (89%)	$\chi^2 = 22.6, p < .001$ OR = 12.16, [3.44, 46.33]
Income < \$20K	58 (33%)	10 (22%)	28 (39%)	92 (76%)	52 (83%)	-	-	96 (33%)	144 (78%)	$\chi^2 = 85.3, p < .001$ OR = 7.46, [4.83, 13.21]
No College	23 (11%)	1 (2%)	12 (16%)	25 (27%)	-	-	-	36 (11%)	25 (27%)	$\chi^2 = 13.7, p < .001$ OR = 2.96, [1.28, 9.66]
Non-White	24 (12%)	4 (9%)	25 (34%)	53 (40%)	-	-	-	53 (17%)	53 (40%)	$\chi^2 = 3.4, p = .06$ OR = 3.30, [0.61, 19.75]
Poor Insight	-	-	12 (16%)	54 (41%)	70 (65%)	73 (53%)	28 (55%)	12 (16%)	225 (52%)	$\chi^2 = 15.5, p < .001$ OR = 5.94, [2.24, 16.58]

Note: Age is shown with M (SD); all other measures are shown with Frequency (%). Percentages were based on all available data for each measure. Bracketed numbers are 95% CI for the research vs. community comparison.

**Table 3.** Clutter Volume and Functional Impairment Across Samples, M (SD) or Frequency of Difficulties (%)

Measure	Research Samples				Community Samples			Comparison: Research vs. Community		
	Frost N = 217	Tolin N = 46	Woody N = 74	Boston N = 132	Hamilton N = 108	Vancouver 1.N = 138	Vancouver 2 N = 109	Research N = 337	Community N = 487	
CIR	3.8 (1.6)	3.8 (1.7)	3.9 (1.4)	4.4 (1.7)	-	-	6.3 (1.2)	3.8 (1.6)	5.3 (1.7)	$\chi^2 = 4.7, p = .03, b = 1.50, [0.21, 2.80]$
Mobility	104 (64%)	30 (75%)	47 (64%)	88 (77%)	70 (65%)	110 (80%)	-	181 (66%)	268 (74%)	$\chi^2 = 3.5, p = .06$ OR = 1.49, [0.87, 2.40]
Kitchen	73 (45%)	20 (50%)	36 (49%)	37 (32%)	67 (64%)	53 (38%)	-	129 (47%)	157 (44%)	$\chi^2 = 0.1, p = .71$ OR = 0.88, [0.40, 1.94]
Bathroom	26 (16%)	9 (23%)	4 (6%)	9 (8%)	28 (27%)	18 (13%)	-	39 (14%)	55 (15%)	$\chi^2 = 0.03, p = .85$ OR = 1.09, [0.35, 3.53]
Structural	19 (12%)	5 (13%)	-	9 (8%)	30 (38%)	5 (4%)	-	24 (12%)	44 (13%)	$\chi^2 = 0.002, p = .97$ OR = 1.03, [0.14, 8.41]
Utilities	5 (3%)	1 (3%)	-	8 (7%)	3 (3%)	14 (10%)	-	6 (3%)	25 (7%)	$\chi^2 = 3.2, p = .08$ OR = 2.44, [0.77, 7.85]
Squalor	29 (18%)	4 (10%)	-	58 (50%)	61 (57%)	68 (49%)	-	33 (16%)	187 (52%)	$\chi^2 = 61.5, p < .001$ OR = 5.50, [3.64, 8.80]
Fire Hazards	51 (32%)	7 (18%)	-	52 (45%)	38 (44%)	67 (49%)	-	58 (29%)	157 (46%)	$\chi^2 = 16.1, p < .001$ OR = 2.14, [1.48, 3.33]
Fire Safety	63 (39%)	14 (35%)	14 (19%)	71 (62%)	96 (90%)	80 (58%)	-	91 (33%)	247 (69%)	$\chi^2 = 11.0, p < .001$ OR = 5.96, [1.75, 21.74]

Note: CIR (Clutter Image Rating) score is average of ratings for kitchen, living room, and main bedroom except for Vancouver 2 which used one global rating. See Table 1 for details on the coding of the functional impairment variables. Bracketed numbers are 95% CI for the research vs. community comparison.

Hierarchical Mixed-Effect Logistic Regressions Predicting Occurrence of Squalor and Fire-Related Concerns in Frost (N = 217), Tolin (N = 46), and Boston (N = 132) Data

Table 4.

Predictors	Odds Ratio (95% CI)			
	Mobility	Squalor	Fire Hazards	Fire Safety
Intercept	$B (SE) = 2.3 (0.5)$	$B (SE) = -2.0 (0.5)$	$B (SE) = -1.3 (0.4)$	$B (SE) = -0.5 (0.4)$
Step 1: Demographics	$R^2 = .09, \chi^2(6) = 15.0$	$R^2 = .08, \chi^2(\phi) = 10.7$	$R^2 = .08, \chi^2(\phi) = 10.7$	$R^2 = .06, \chi^2(\phi) = 10.7$
Age	1.01 [0.98, 1.05]	0.97 [0.94, 1.01]	1.01 [0.98, 1.04]	0.99 [0.96, 1.02]
Male Gender	0.65 [0.29, 1.44]	1.27 [0.55, 2.86]	0.59 [0.26, 1.27]	0.89 [0.41, 1.93]
Not Partnered	0.56 [0.22, 1.34]	1.33 [0.49, 3.90]	1.01 [0.44, 2.37]	0.97 [0.41, 2.27]
Not Employed	0.64 [0.28, 1.43]	0.55 [0.22, 1.34]	1.45 [0.67, 3.17]	0.91 [0.42, 1.98]
Income < \$20,000	1.95 [0.82, 4.77]	1.87 [0.79, 4.55]	1.15 [0.52, 2.54]	1.49 [0.66, 3.38]
No College	0.65 [0.21, 2.10]	0.66 [0.21, 1.85]	1.20 [0.47, 2.98]	0.68 [0.25, 1.82]
Step 2: Clutter volume	$R^2 = .59, \chi^2(J) = 78.7$	$R^2 = .25, \chi^2(J) = 27.9$	$R^2 = .29, \chi^2(J) = 38.5$	$R^2 = .50, \chi^2(J) = 81.8$
Clutter Image Rating	<b>3.92 [2.69, 6.10]</b>	<b>1.79 [1.41, 2.31]</b>	<b>1.88 [1.51, 2.39]</b>	<b>2.91 [2.18, 4.04]</b>
Step 3: Sample Type	$R^2 = .61, \chi^2(J) = 1.7$	$R^2 = .39, \chi^2(J) = 6.6$	$R^2 = .30, \chi^2(J) = 0.3$	$R^2 = .51, \chi^2(J) = 1.8$
Community Sample	0.54 [0.15, 1.41]	<b>4.69 [2.00, 15.12]</b>	1.22 [0.53, 4.42]	1.73 [0.78, 3.95]

Note.  $\chi^2$  tests are likelihood-ratio test comparing deviance (-2LL) of current model to that of baseline or previous model. Bold =  $p < .05$ .