

Challenges in the Remediation of Compromised Housing Situations in Individuals  
Exhibiting Hoarding Behaviours

by

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### Abstract

Hoarding has been estimated to affect 2 to 5 percent of the population. There are considerable health and safety implications for those who hoard, others living with them, and for the community. For this reason, public health inspectors (PHIs) respond to situations involving vulnerable individuals living in these potentially adverse housing situations. Earlier research found that PHIs responding to these housing health hazards face many challenges in the remediation of these conditions including client health, structural factors, and policy issues.

The purpose of this case study, approached from a social constructionist perspective, is to further explore the challenges in remediation of compromised housing health hazards in hoarding situations. The study included PHI's documented reports of 40 cases referred to them between 2013 and 2015 as well as field observations and semi-structured interviews with an individual who hoards, his family, members of agencies involved with this case, and PHIs who respond to hoarding cases. This data is part of a larger two-year case study examining an Environmental Health Division's response to housing health hazards in vulnerable populations.

There were significant challenges in the remediation of hoarding. Client factors such as advancing age, infirmity, living alone, and lack of formal and informal supports hampered resolution of cases as did lack of training for PHIs about hoarding and its psychological ramifications. The lack of coordination of services within the City of Greater Sudbury, the magnitude of the cleanup required, and the chronic nature of hoarding also posed difficulties. The creation of a coalition to provide a more comprehensive response to hoarding is required to support this vulnerable population.

*Keywords:* hoarding, self neglect, public health, social construction

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## Introduction

“David’s had a stroke and is back in hospital. I am going over to visit him later so that I can obtain permission to enter his house to check on the pipes. With this cold snap, they may have frozen” were the words of the public health inspector. With permission granted, the inspector and I were off. This was my first exposure to a house consumed by hoarding and it was a shock. The inspector and I entered the home in single file along a narrow pathway. The temperature in the living room was just above freezing as the furnace was not on. There was a small electric space heater running by the only available chair. How the place had not gone up in flames was a mystery. There was shredded paper everywhere with multiple extension cords traversing the main floor, wound throughout the clutter. The back door was wide open and the kitchen was frigid. There was a strange sound toward the back of the house which, upon further investigation, was indeed due to burst pipes; there was a waterfall in the basement. The public health inspector shut off the water and disengaged the electrical supply to the house. Debris was cleared away from the back door and it was closed. David’s dog had already been removed by animal control but there was still an abundance of critters; mice scurried around, poking their heads out of the chaos created by piles of stuff. The house clearly was not habitable, especially now that the pipes had broken. This created a problem because David wanted to return home and the hospital was already planning his discharge. His stroke had only affected his speech; he was still able to get around.” (Excerpt from a fieldnote).

As the media has taken an interest in both reporting and sensationalizing self neglecting behaviours including hoarding, the public is becoming more knowledgeable about this condition and we, as a society, are becoming more concerned about the effects of these behaviours for both

the individual exhibiting the behaviours and the community at large. Although individuals exhibiting the behaviour often do not seek help for this condition, others seek assistance on their behalf. This thesis will explore the challenges in the remediation of hoarding situations of vulnerable individuals that have come to the attention of public health inspectors (PHIs).

In the Sudbury area, PHIs at the Sudbury and District Health Unit (SDHU) receive requests from the public and other service providers to attend homes where health hazards may be present. Some of these requests involve vulnerable individuals exhibiting self neglecting behaviours which may include hoarding. Factors such as poor health, physical limitations, social exclusion, unemployment, food insecurity, and poverty may intersect to compound the challenges of these individuals, making it difficult for them to remedy their situations, causing these hazards to escalate. The SDHU becomes involved when the situation reaches the point when a citizen or service provider is concerned enough to make a referral to them. Although the governing legislation of the public health inspector, the Health Protection and Promotion Act (HPPA) (2016) does not specifically outline a role for the PHI with respect to responding to a potential health hazard in a private residence and the regulations are often subject to interpretation, the Environmental Health Division of the SDHU is committed to responding to these requests in an effort to contribute to a healthy living environment for all. In the area served by the SDHU between January 2013 and December 2015, 94 cases were opened by inspectors involving vulnerable individuals living in potentially adverse housing conditions. Although PHIs often refer those in need to appropriate services such as by-law enforcement, fire, building, or health authorities, these inspectors are concerned that additional supports may be necessary, especially given that they receive repeat calls to some homes.

### **Background Information**

Because of my concern about the lack of coordinated services in the Sudbury area for individuals exhibiting hoarding behaviour, I conducted a preliminary literature search which revealed the following themes: 1) history of hoarding and its inclusion in the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-5); 2) condition of homes of hoarders; 3) prevalence of hoarding and concurrent disorders; 4) rationale for hoarding; 5) impacts on the individual; 6) impacts on the community; 7) complaints to health departments; 8) solutions for addressing hoarding; and 9) the need for community collaboration. An example of a northern Ontario community response by public health inspectors investigating potential housing health hazards is included to illustrate local concerns.

### **History of Hoarding and its Inclusion in the DSM-5**

For more than a century, hoarding has been known to exist but it was not until 1996 that Frost and Hartl developed a set of criteria defining hoarding which then became adopted by researchers. They considered hoarding to include:

- 1) the acquisition of and failure to discard a large number of possessions that seem to be useless or of limited value; 2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; 3) significant distress or impairment in functioning caused by hoarding (Frost & Hartl, 1996, p. 341).

In the past, hoarding was often considered a symptom of obsessive compulsive disorder (OCD) and was included in scales measuring obsessive compulsive symptoms but was only included in the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition, text revision (DSM-IV-TR) as one of the eight criteria for obsessive compulsive personality disorder (Mataix-Cols et al., 2010). This criterion made no mention of the term “hoarding” but described “the

inability to discard worn-out or worthless objects even when they have no sentimental value” (American Psychiatric Association, 2000 as cited in Mataix-Cols et al., 2010, p. 557). It is thought that hoarding was first included in the DSM-IV-TR as a symptom of OCD because of its inclusion in the Yale-Brown Obsessive Compulsive Scale, a scale used in the DSM-IV field trials (Mataix-Cols, et al., 2010). Its use in the trials resulted in the Yale-Brown scale becoming the most widely used scale for OCD. As a result, many of the initial studies on hoarding used participants diagnosed with OCD but it has been subsequently determined that not all hoarders are considered to have this disorder (Mataix-Cols, et al., 2010). Because the results of many studies have demonstrated that hoarding is not common to all individuals with OCD, it was thought by Mataix-Cols et al. (2010) that hoarding deserved its own classification in the DSM. Hoarding is now listed in the DSM-5 as its own disorder and is defined as “persistent difficulty discarding or parting with personal possessions, even those of apparently useless or limited value, due to strong urges to save items, distress, and/or indecision associated with discarding” (American Psychiatric Association, 2013, p. 1). According to the DSM-5 (American Psychiatric Association, 2013) hoarding behaviour results in clutter in the lived in areas of a home, yard, or workplace which precludes normal use and this can cause significant distress. For an individual to be considered as having a hoarding disorder he or she must not have a concurrent medical condition such as a brain injury and the hoarding must go beyond the symptoms of another mental disorder. It is also suggested in the DSM-5 that it be specified in the diagnosis if hoarding is accompanied by excessive acquisition as well as an indication of whether the hoarder has good, fair, poor or delusional insight into the problematic nature of their hoarding behaviour despite evidence to the contrary (American Psychiatric Association, 2013).

The need for including hoarding disorder in the DSM-5 can be questioned. A committee of some of the top hoarding researchers worldwide were commissioned by the DSM-5 Anxiety, Obsessive-compulsive Spectrum, Posttraumatic, and Dissociative Disorders Work Group to put forth their reasons why this inclusion was necessary and their logic for inclusion follows (Metaix-Cols et al., 2010). First, epidemiological studies using accepted scales such as the Savings Inventory-Revised and the Hoarding Rating Scale Self-Report, which include the proposed diagnostic criteria for hoarding, have shown the prevalence of hoarding to be between two and five percent of the population. This represented a significant proportion of the population yet hoarding continued to go unrecognized and untreated. Risks to individuals who hoard are significant in terms of distress or disability. Research has shown that hoarding originates from deficiencies in making decisions, categorization, organization, memory, emotional attachment to possessions, avoidance behaviour, and erroneous beliefs about the value of possessions. Neuroimaging studies have located unusually low activity in the cingulate cortex of hoarders. Often hoarders are not bothered by their hoarding behaviour but their families often are distressed by the situation and there are issues for society as a whole due to concerns about health and safety. It was concluded by Metais-Cols et al. (2010) that including hoarding disorder would increase public awareness of the nature of the condition which would then lead hoarders to those that are best able to assist with the behaviour. Metais-Cols et al. also suggested that many clients with hoarding difficulties rejected OCD as a diagnosis because they did not feel that they belonged within groups designed for individuals diagnosed with OCD.

It is possible that a diagnostic criterion in the DSM may result in pathologizing the extreme aggregation of possessions. Also, inclusion of hoarding disorder in the DSM-5 may provide unwarranted credibility to the families of hoarders or to social service agencies when

attempting to coerce a hoarder to obtain treatment for a problem which he or she denies exists (Mataix-Cols, et al., 2010). Yet, there is a need for recognition within the medical community that hoarding is a problem that requires a solution (Frank & Misiaszek, 2012). Is it necessary that hoarding be defined as a mental health disorder by its inclusion in the DSM-5? Certainly, this was argued by the selection committee. Inclusion may raise awareness among physicians but as the vast majority of physicians never visit the homes of their clients, it is questionable that they would be a position to diagnose this condition. This is especially true given the denial that so commonly accompanies this condition (Tolin, Fitch, Frost, & Steketee, 2010; Chasson, Carpenter, Ewing & Lee, 2014).

Amongst those who reject the medical model, some may also reject the view that it is a truism that hoarding is a mental health disorder. Certainly, the American Psychiatric Association and its members, may want to construct hoarding as a mental illness but it is also the right of others to reject this designation. For the purposes of this thesis, I will refer to “hoarding behaviour” rather than use the term “hoarder” to make clear my rejection of the medicalization of living among excessive clutter. Clutter, like most things, occurs on a continuum. Although the PHIs do use the word “hoarder”, they more often talk about levels of clutter. For the purposes of this thesis, “hoarding behaviour” or “excessive clutter” results only when living spaces are no longer available for their intended use.

### **Prevalence of Hoarding and Concurrent Disorders**

Although hoarding appears to be more prevalent of late, studies have consistently shown hoarding to affect between 2 and 5% of the population (Frost, Steketee & Tolin, 2011; Samuels et al., 2008). In community-based samples scored for hoarding behaviour (but not specifically targeting hoarding), it was found that hoarding was three times more likely in the oldest versus

the youngest group (Samuels et al., 2008). In a large community sample, Samuels et al. (2008) found that hoarding was inversely related to household income, with the odds of having an individual who exhibits hoarding behaviour in the household four times greater in the poorest versus the wealthiest households. There were twice as many widowed people who hoard than those who were married and twice as many unemployed as employed. Individuals who hoard are three times more likely than non-hoarding individuals to have a parent with psychiatric symptoms (depression, mania, heavy drinking), four times more likely to have lacked security following a home break-in as a child, and four times more likely to have experienced excessive discipline before the age of 16 (Samuels et al., 2008).

Frost et al. (2011) found that hoarding individuals often have concurrent diagnoses of major depressive disorder (50%), generalized anxiety disorder (24%), social phobia (24%), or OCD (20%). Inattentive attention deficit/hyperactivity disorder (ADHD) was found in 28% of hoarders and it is this difficulty with maintaining attention that has been hypothesized to be among the information processing deficits that may underlie hoarding (Frost et al., 2011). Samuels et al. (2008) noted that alcohol dependence was significantly higher in hoarders (52%) than non-hoarders (19.5%).

Hoarders have a higher incidence of medical conditions compared to a matched sample from the general population (Tolin, Frost, Steketee, Gray & Fitch, 2008). Hoarding participants are significantly more likely to be overweight or obese (78% of the sample) and are significantly more likely to report medical histories of arthritis, asthma and other lung conditions, high blood pressure, diabetes, heart attack, stroke, cancer, and autoimmune disorders. Fibromyalgia was found in 11% of hoarders and chronic fatigue in 12% and, although this was not measured in the matched sample, the general population has an incidence of 4.9% and 0.2% respectively.

### Rationale for Hoarding

Quality of life scores calculated from a survey of compulsive hoarders attending a specialized six-week treatment program for clients with OCD and related disorders were found to be lower than the norm (Saxena et al., 2011). The participants felt unsafe in their neighbourhoods and less satisfied with their protection against robbery or attack. Saxena et al. (2011) found that 9% of these hoarders had been victims of violent acts and 23% had experienced non-violent crime as compared to the non-hoarding OCD participants at 4% and 15% respectively. Andersen, Raffin-Bouchal, and Marcy-Edwards (2008) suggest that, while the scorecards used to measure hoarding may expose the nature of the hoarding problem, they are unable to fully explain the underlying social and emotional dynamics that contribute to hoarding behaviour. The authors report many reasons given by participants for their hoarding behaviour. Books and newspapers are stockpiled to relieve anxieties about failing cognition, while food is hoarded to relieve anxieties about experiencing a shortage without the stockpiled items. Newspapers help the one who hoards to feel connected to the world around them even while they are physically isolated. For many older individuals, hoarding replaces paid work and makes them feel worthy. Hoarding provides a sense of control for those who hoard. He or she clings to the perception that all is well while declining offers of assistance to declutter. Often individuals who hoard set out rules for anyone entering their home, further increasing their sense of control (Andersen et al., 2008). It is ironic that individuals who hoard create problematic conditions similar to those they are trying to remedy. Newspapers and magazines are used as a means to stay connected to the world but the clutter from saved paper results in friends and family not wanting to visit. Items are stockpiled so that the hoarder will not go without, but specific articles

cannot be found when required. Hoarders become controlled by their environments rather than controlling their environments.

### **Impacts of Hoarding on the Individual**

Hoarding impairs the health and safety of the individual, his or her family, friends, and others living nearby (Bratiotis, 2013; Buscher, Dyson, & Cowdell, 2014; Chapin et al., 2010; Franks, Lund, Poulton, & Caserta, 2004; & Tolin, Frost, Steketee, & Fitch, 2008). Increasingly, evidence has associated housing quality with morbidity from infectious diseases, chronic illness, injuries, poor nutrition, and mental disorders (Krieger & Higgins, 2002). Vermin can carry vector-borne illnesses such as Hantavirus, Lyme disease, or West Nile virus that can place the entire community at risk (Fleury, Gaudette & Moran, 2012). Infectious diseases can be spread by a lack of hot water for washing dishes, lack of food waste disposal, infestation by rodents and insects, and inadequate food storage (Krieger & Higgins, 2002). Chronic diseases such as asthma and other respiratory illnesses are associated with damp, cold, and mouldy housing (Krieger & Higgins, 2002) as is frequently the case in hoarding households for as many as 40% have no heat (Arluke, Frost, Carter & Messner, 2002). Dirty, old carpeting can act as a reservoir for dust, allergens, and toxic chemicals which can contribute to respiratory illnesses as well as neurological and hematologic illnesses (Krieger & Higgins, 2002). Damp, mouldy, and cold housing has also been associated with anxiety and depression and this is exacerbated by the fear of homelessness due to eviction (Krieger & Higgins, 2002).

Animal hoarding, found in 32% of cases, presents a greater threat (Frost, Steketee & Williams, 2000). Chapin et al. (2010) found dead and dying animals in 6% of the homes of hoarders. These homes have been reported to have floors coated, often several inches thick, with human and animal urine and feces (Arluke et al., 2002). Hoarders often live with other humans,

putting them at risk as well. Risk of infection is substantial in these homes, especially for those who are frail and immunocompromised. Although risk to human inhabitants is great, the risk to the animals involved is even greater. The hoarder's ability to feed and care for their animals is severely compromised where the number of housed animals can average 50 or more (Arluke et al., 2002). In cases of animal hoarding, there is a risk that the animals will be seized due to violation of animal protection laws (Frost et al., 2000).

The severity of compulsive hoarding increases with age, and the frailty of elderly hoarders increases their risk of falls (Chapin et al., 2010). The problems associated with falls include broken hips, hospitalization, surgical repair, admission to nursing facilities, and premature death (Marks, Allegrante, MacKenzie & Lane, 2003).

Lucini, Monk, and Szlatenyi (2009) found that 67% of hoarding homes are a fire hazard. In their study of house fires in Australia they found that, even though fires in hoarding households only made up 0.25% of fires, they were responsible for 24% of all preventable fire fatalities. The value of damage by fire to a home where hoarding is present is eight times greater than a home where hoarding is not present (Lucini et al., 2009).

Homelessness is a major risk for those with hoarding disorder. Rodriguez et al. (2012) suggest that, even though mental health services to homeless individuals have expanded greatly in the last ten years, there is little attention given to the primary prevention of homelessness. Eviction is a major cause of homelessness (Rodriguez et al., 2012) with eviction due to code enforcement in hoarding situations reported to be as high as 20% (Frost et al., 2000). Untreated mental health problems can increase the risk of eviction by contributing to behaviours that jeopardize tenancy (Rodriguez et al., 2012; Crane et al., 2005) such as violations of building, fire, or property maintenance codes (Whitfield, Daniels, Flesaker & Simmons, 2012). Clutter

promotes pest infestation and blocks fire exits endangering both the hoarder and their neighbours' safety. In the most serious hoarding cases, the buildings where the hoarders reside have to be condemned (Frost et al., 2000).

### **Impacts of Hoarding on the Community**

Not only are individuals who hoard at risk but so, too, are visitors to their homes. The disorganized living spaces create safety hazards for first responders to medical and fire emergencies (Lucini et al., 2009, Schorow, 2012, Bratiotis, 2013). Agency personnel working in the homes of individuals who hoard have reportedly suffered from insect bites, irritated eyes, sore throat, and sinus problems aggravated by mould (Chapin et al., 2010). Ammonia from urine is a potent eye and respiratory irritant and, in the case of animal hoarding, a visitor may require a protective breathing apparatus to enter the home of an individual who hoards (Arluke et al., 2002).

The risks associated with hoarding extend into the community as infestations can spread beyond the walls of a hoarding household. In one case of animal hoarding involving dogs, a nearby school had to be closed because of a flea infestation emanating from the hoarding household (Arluke et al., 2002). Risks due to spreading infestation and fire are even higher in inner city areas because of population density (Brown & Pain, 2014). More than half of hoarding households have clutter extending outside the walls of their homes (Frost et al., 2000). A study of code enforcement officials reported that 57% of hoarding households were deemed to be a health risk to the community (McGuire, Kaercher, Park, & Stiorch, 2013). Once an individual's hoarding behaviour has negative consequences for the community, this private matter may be reported to the public sector (government agencies and organizations) and it is the expectation

that agencies such as housing and code enforcement, police, fire, animal control and public health will act to lessen these negative consequences (Chapin et al., 2010).

### **Complaints to Health Departments**

Complaints to health departments come from neighbours, fire personnel, police, social service agencies, and service personnel visiting the homes (Frost et al., 2000; McGuire, Kaercher, Park, & Storch, 2013). Frost et al. (2000) found that only half of the individuals who hoard recognized the lack of sanitation in their homes even though health officers listed 88% of the homes as unsanitary because hoarding interfered with basic hygiene and food preparation. These cases typically involve multiple agencies at significant cost to the communities. In this study, health departments made between zero to 12 visits, with an average of three repeat visits to each home. Additional agencies were involved in 79% of cases and almost half of these cases involved three or more agencies. The most frequent referrals were to fire departments (59%), departments of aging (as found in the United States) (40%), mental health services (31%), animal welfare (16%), and child welfare (5%). Forty percent of the individuals involved refused to cooperate and had some or all of their possessions removed by the city. In nearly half of these cases, the buildings where hoarding was present were condemned or the tenants were evicted, with a third moving to assisted living facilities and with the others potentially being rendered homeless. Frustration was reported by health officers as inconsistent judicial rulings complicated case resolution.

### **Solutions for Addressing Hoarding**

Individual treatment for hoarding has shown to have limited success and is costly to administer due to its intensive nature (Steketee, Frost, Tolin, Rasmussen & Brown, 2010). Individuals who hoard may seek treatment at the behest of others as those who hoard lack insight

into their problems and are often in denial (Tolin et al., 2010). Many individuals who hoard tell clinicians that their only problem is that others will not stop pressuring them about changing their behaviour (Tompkins, 2011). Because hoarding, which begins as an individual problem, often becomes a community problem, many municipalities have designed multidisciplinary task forces to tackle hoarding (Chapin et al., 2010; Bratiotis, 2013; Brown & Pain, 2014; Koenig, Spano, Leiste, Holmes, and MacMillan, 2014). Since forced cleanout of a home consumed by hoarding is ultimately unsuccessful in the long term, these forced cleanouts are now less likely to be prescribed by some housing or fire authorities (Brown & Pain, 2014; Whitfield, Daniels, Flesaker, & Simmons, 2012). It is necessary, however, to declutter as the accumulation of materials can lead to rodent or other infestations, fire hazards, falls, asthma, and infections (Chapin et al., 2010; Krieger & Higgins, 2002; Lucini et al., 2009). Tompkins (2011) suggests that this harm reduction approach to treatment can be more successful than a full blown cleanout because it obviates the requirement of acceptance of treatment. Acceptance of treatment emphasizes discarding the majority of the hoarded possessions and arresting the hoarding behaviour. In contrast, harm reduction instead promotes discarding only what is necessary to make the living environment safe and comfortable. It has been shown that the addition of a social worker to a team assembled to combat hoarding is most beneficial for many reasons (Bratiotis, 2013; Brown & Pain, 2014, Koenig et al., 2014). Social work, as a profession, has a history of working with involuntary clients, both from a social control and a therapeutic stance, thus enabling them to be well prepared to achieve balance between these two poles. It is expected that this may be required when assisting individuals who hoard.

**A study of Responses to Hoarding Situations in Northeastern Ontario**

A study of public health inspectors from Environmental Health Divisions in northeastern Ontario found many challenges when responding to requests for inspection of possible health hazards in homes of individuals who self-neglect (of which hoarding is an extreme example) (Lefebvre et al., 2012). One site within the study estimated that public health inspectors spent approximately one third of their time addressing these complaints even though they questioned their mandate in many of these cases. The public health inspectors reported difficulty in knowing what to do with some referrals because of the lack of clarity in the HPPA about what a health hazard actually is and whether it applies to an individual or only applies when the hazard extends into the community. They viewed strong community partnerships with referral agencies and municipal bylaw and property standards officials as positive but, without these, the public health inspectors believed that some vulnerable individuals were at risk of falling through the cracks.

Both the vulnerable people and the public health inspectors were aware of and concerned about the potential for homelessness. The individuals experiencing housing health hazards were considered vulnerable, and were often unwilling to make complaints to their landlords for fear of eviction (Lefebvre et al., 2012). The public health inspectors were frustrated by their inability to resolve many of these cases even when they went above and beyond their responsibilities when attempting to broker resolution of these issues. They found that many of the difficulties faced by their clients occurred as a result of their socioeconomic status or geographical isolation, conditions for which the public health inspectors had no solution.

**The Need for Community Collaboration**

This preliminary literature review suggests that there are serious concerns about the support available to vulnerable individuals living in housing situations potentially hazardous to

their health. Some of these individuals live in conditions that most would find unfit for human habitation. Although there have been attempts to assist these individuals, clearly there are few long term solutions available to the residents of Sudbury and the surrounding area. Public health inspectors have reported difficulty in resolving many of these cases because the lack of clarity in the legislation regarding their mandate makes them fearful of potential liability issues (Lefebvre et al., 2012). These inspectors realize that they require community support but this is often unavailable. Social workers, who are trained to work with vulnerable populations, often do not have the flexibility to visit clients in their own homes. Task forces that include social workers on their teams have been beneficial in some urban municipalities (Brown & Pain, 2014; Whitfield et al., 2012) but have not been used in the area served by the SDHU. Community collaboration has been said to be the very thing that successfully reforms health systems because of its shared responsibility, team approach, and increased pool of resources (Whitfield et al., 2012). It is consistent with ecological theory which suggests that both the causes and solutions of health and social problems lie beyond the individual and can be associated with such social determinants as available health care and social services (Whitfield et al. 2012). When a group of agencies join together to support a vulnerable population, potential is created for an approach that builds upon the strengths not only of the vulnerable but of the service providers as well (Whitfield et al., 2012). It is necessary to comprehensively examine the difficulties inherent in the situation of vulnerable individuals living in conditions potentially hazardous to their health, from the perspective of all those involved, so that the challenges to resolution of these cases can be discovered from multiple points of view.

### **Deficiencies in the Literature**

The literature concerning hoarding is sparse and most originates in the United States and the United Kingdom where laws about intervening in cases of self-neglect and hoarding are different than those in Canada. The literature is also lacking in studies looking at solutions for smaller, rural, and remote communities. Most of the literature available is written from the perspective of the medical model which provides information but does not seek to understand the complex nature of hoarding behaviour. Although there is some literature from a qualitative perspective, few case studies were located. For these reasons, it is important to approach this topic from a social constructionist perspective, an approach where it is understood that individuals create their own meaning of their situation. A case study approach provides the opportunity for an in-depth view of hoarding behaviour using multiple types of data sources and multiple points of view. This type of approach gives a voice to the vulnerable that is not often heard and, therefore, will provide new knowledge about hoarding. Using cases referred to the SDHU's Environmental Health Division, the focus of this study will be on an organization that services many rural and remote communities over a vast territory. It will provide a detailed analysis of the interaction between the PHIs and those displaying hoarding behaviours as well as those who refer hoarders to this service. It will also detail the barriers in remediating the housing situation for these clients. This information—as part of a larger study—will be available to inform practice and provide data for policy development for the SDHU and other stakeholders.

The purpose of this study is to describe the hoarding behaviours of vulnerable individuals being investigated by a public health inspector for potential housing health hazards and the health unit response to the situations.

## **Research Question**

The research question is as follows: What factors hinder or prevent the resolution of hoarding situations referred to the SDHU Environmental Health Division?

## **Method**

This case study includes documentation, interviews, and field observations. Records of those vulnerable individuals referred to the SDHU within a three-year period for the investigation of housing health hazards created by self-neglecting behaviours including hoarding were used to gauge the scope of the problem. Interviews with PHIs responding to these referrals, interviews with available referral sources, and an interview with an SDHU client exhibiting hoarding behaviour as well as close contacts, personal and agency, of this individual were conducted. Observations were made in the field by accompanying a PHI as he inspected the home of an individual exhibiting hoarding behaviour. Additional field observations were documented while accompanying other PHIs on their calls to develop a greater understanding of the interactions between PHIs and their clients.

## **Philosophical Interpretive Frameworks**

This research was conducted from a social constructionist worldview. This worldview suggests that individuals not only make meaning of situations within their lives but also construct meaning within interactions with others. The concept of self-neglect is a social construct as it reflects what society expects an individual to conform to in the areas of personal and environmental hygiene and cleanliness (Iris, Riding, & Conrad, 2010). By using open ended questions and by being mindful of my position within the research it my was intent to record the construction of meaning by the participant considered to be exhibiting hoarding behaviours as

well as that of the PHIs, agency contacts, and family who were expected to construct meaning similar to the mores of society.

### **Characteristics of Qualitative Research**

Qualitative research is used over quantitative research for a problem that requires exploration to understand its complex nature. Therefore, the proposed study used a qualitative approach. Qualitative research is useful for exploring and understanding the meaning given to a phenomenon by individuals (Creswell, 2014). Data is often collected, using open ended questions, in the participant's setting and data analysis is inductive based upon emerging themes (Creswell, 2014). Creswell (2013) suggests that the researcher using a qualitative design should follow a procedure that is "inductive, from the ground up, rather than handed down entirely from a theory or from the perspectives of the inquirer" (p. 22). Qualitative researchers use theoretical frameworks to inform their study rather than devising a hypothesis as one would in quantitative research (Creswell, 2013).

### **Qualitative Approach Used**

This research used a specific type of qualitative inquiry: the case study. A case study examines a context, bounded by time and place, through detailed data collection from multiple sources, including observations, interviews, documents and reports (Creswell, 2013). Reporting on a case study provides the opportunity, not only to describe the case, but also to identify themes arising from the intersection of differing sources of data (Creswell, 2013). The case study approach is an especially good methodology to use within a constructivist framework in that it allows participants to express their own meanings about a situation. In this study, the case includes the interactions and relationships between vulnerable clients who exhibit hoarding behaviours, public health inspectors, referral sources, involved social service agencies, and

family members. Case studies are particularly valuable when studying relationships (Abma & Stake, 2014). As a part of the research, I recognize that I also constructed meaning in the interaction with all the participants I interviewed and constructed meaning in the analysis phase of the research. Of course, there is always pressure applied from outside the case. This includes policy and procedures as well as the diagnosis of “hoarder” as imposed by the medical community.

In this investigation, one individual and the supports around this individual are being studied. It is commonly thought that one cannot generalize from such a small sample. Eysenck suggested early on that case studies produce nothing more than anecdotes but, upon further reflection, realized that “sometimes we simply have to keep our eyes open and look carefully at individual cases—not in the hope of proving anything, but rather in the hope of learning something!” (as cited in Flyvbjerg, 2006, p. 224). By examining the interaction between an individual exhibiting hoarding behaviour and his environment, I was sure to learn much about what is working, what is not working, what needs to be improved, and, ultimately, what specific kinds of improvements might be made.

### **Issues of Personal Biography**

It is necessary for me to declare my position as it relates to the research at hand. I am a white female which I know affords me privilege. This is compounded by the fact that I recently retired from 28 years of self-employment as a dentist. I recognize that my income during that period was far in excess of that of the average Canadian and this, too, will alter my perception of the world. Although I have never worked as a social worker, I consider myself a social worker given my recent training in the Bachelor of Social Work and Master of Social Work programs. Given that the topic of this thesis involves vulnerable individuals, I believe that I have a bias, in

that I believe social workers are well trained to work with this population, and may be the preferred discipline to work with this group.

Although I would have considered myself poor growing up, I have never been precariously housed. I have never been in the situation of being considered vulnerable or been in the situation where my housing required remediation because of health hazards. As a teen, I had experience working within a home where I was tasked with cleaning pathways between extreme piles of clutter. At the time I viewed the behaviour of the homeowner as eccentric, but she was a loveable older woman and I enjoyed being with her. One of my maternal aunts also exhibited hoarding behaviour, but again, she was just considered, by my family, to be an eccentric “old maid”. I do not think that these experiences influenced my decision to undertake this research but I find it ironic that I was exposed to two examples of hoarding in my youth, long before it gained public notoriety. In fact, studying hoarding was not of particular interest to me. My interests lie more in the field of addiction but in studying hoarding, I found a large number of similarities between addiction and hoarding, denial being one of the hallmarks. I find it unacceptable that the area in which I live does not have a protocol in place to address hoarding. There is no coordination of service and little to no assistance available to individuals who may be at risk for poor health outcomes or eviction due to their behaviour. There are also implications for the greater community that are being overlooked. I am seeking to define the problem as it exists in the area served by the SDHU and to propose solutions that will allow for a smoother trajectory in the referral of individuals in need of assistance due to their hoarding behaviours. A further interest I have in this research lies in the construction of hoarding as a disorder with both medical and social implications. In my transition from a career in the dental profession to one in the social work field I know that I have to change the way that I approach situations, leaving behind

the medical model and embracing a social constructionist framework, and this research offered me that opportunity.

### **The Positivist Medical Model versus Social Construction**

Having been educated in the medical model of health care, both in research and delivery, I was surprised to learn in my undergraduate social work education that there were other schools of thought. I did not enter the School of Social Work until I was 48 years old and, at the time, my belief in positivism was deeply entrenched. It quickly became apparent that I had to change my way of thinking. Having embraced the mantra “randomized, controlled, clinical trials are the gold standard” I was in for a rude awakening as I was challenged on this thinking almost immediately. With such a poor understanding of social work, its values, and of qualitative research, I was not easily swayed. Throughout my education I had gained exposure to positivist, post positivist, and social constructionist paradigms but I still did not fully comprehend the theoretical differences. To “know” anything, I believed that one had to randomly select a group to study, select a variable, control for everything else, apply the variable, and wait for results. To ask a single individual for an opinion and base research findings on the reply seemed preposterous. I was being told, though, as Casstevens (2010) has eloquently stated, that “[s]ocial workers need to avoid having the deficit based, problem-saturated, and pathologizing language of the medical (or any other) model dominate their practice” (p. 385). I had a lot to learn.

Fortunately, my thinking has changed. I still want new medications tested using randomized, controlled, clinical trials but I no longer believe that this methodology is the only way to determine a course of action. For me, a large part of my learning in the process of conducting the social work research required to complete my thesis had to include the use of qualitative research methodology. I considered it necessary to break away from my positivist

teachings to embrace social constructionism as the overarching paradigm. To increase my chances of staying true to my newfound ideology, I decided that it was important to learn more about qualitative research from a social constructionist viewpoint prior to the commencement of my study.

Thinking that I was not the only one to have had this conflict, I decided it prudent to spend some time examining the literature to find what others who have struggled with the same difficulty have said and done. Lincoln (1992), early on in this debate, suggested that

Qualitative methods are generally those nonquantitative methods that attempt to grasp phenomena in some holistic way or to understand a phenomenon within its own context or to emphasize the immersion in and comprehension of human *meaning* ascribed to some set of circumstances or phenomenon or all three. (p. 376)

This definition spoke to me because I think that it is important to look at behaviour in a holistic way, including the environment of the individual. Looking for the meaning that the individual ascribes to his or her situation facilitates the use of a social constructionist approach. If complex human behaviours are researched using simplistic linear models, the research will provide “simplistic, linear results” (Lincoln, 1992, p. 378). Lincoln further suggests that health and medicine are human constructs and if one changes the construct, one can change the behaviour, and ultimately the health of an individual.

Epistemologically, the positivist studies something without influencing it or being influenced by it while searching for the truth (Lincoln, 1992). Social constructionism suggests that “reality is constructed and reconstructed both individually from the sum of experience and in relationship and conversation with others” (Ward, Hoare, & Gott, 2015, p. 454). The construction of meaning within a case study by researcher and participants is inconsistent with

the positivist idea of objective truth as the goal of research. I accept that a social constructionist approach to research incorporates the researcher in the meaning making of the participants rather than the researcher remotely observing and reporting. It is for that reason that I have outlined the essence of my personal biography and explained how my history may have affected both my interaction with the participants as well as my interpretation of their words within my analysis.

This discussion would not be complete without a discussion about the medicalization of illness. Medicalization results when we define human problems or experiences as medical problems that require a diagnosis and it occurs through a process where this diagnosis is formed, becomes accepted by the medical community as valid, and is then used to define the problems of our patients and clients (Conrad and Barker, 2010). One of the great problems with medicalization is that it promotes medical solutions while ignoring or downplaying the social context in which the problems that individuals face are located (Conrad and Barker, 2010). Healy (2005) argues that the medical model approach to social work practice ignores the underlying structural causes of an individual's problem and instead focuses on changing the individual rather than altering the environment. Social constructionism provides an alternative to the deterministic logic of the field of medicine which can then be used to clarify what needs to be considered when formulating policy. Conrad and Barker (2010) suggest that it is imperative for us to continuously ask ourselves “[w]hat is the definition of the problem upon which this policy is based, how was it developed, and what are the consequences of adopting this definition?” (p. S76).

I have stated that social constructionism is the overlying paradigm that directed my research. Marlow (2011), a social worker, suggests that “[p]aradigms function as maps, directing us to the problems that are important to address, the theories that are acceptable, and the

procedures that are needed to solve the problems” (p. 8). It is important to keep in the foreground, the premise as discussed by D’Cruz and Jones (2004), that social work research “is not solely or primarily conducted as a pursuit of knowledge but also has a political and ethical purpose in keeping with social work objectives to achieve social justice and improve the social conditions of individuals, groups, and communities” (p. 30).

I came to this research by way of a mid-life crisis. After working as a dentist for almost a quarter of a century I decided to return to school to obtain a social work degree. Although my body was giving out due to the punishment it endured in my first career, my mind was still strong. I enjoyed working with people and did not want to give that up. In my first career I frequently worked with vulnerable individuals and found this population very rewarding, so pursuing a career in social work seemed like the perfect fit. Because of my late start, I elected to pursue my Master of Social Work before ever working in the field. I knew that this would present its own unique challenges. Conceptually, my entire career centred on the medical model of health care delivery. I had never heard of the bio-psycho-social model of care, which was unfortunate, because it would have been of great benefit to me as a dentist. This thesis needed to be based on qualitative research from a social constructionist perspective to satisfy my need to learn to think differently. My focus was more on the research process than on a specific topic. An opportunity was presented to me by the SDHU to assist them with a case study of housing health hazards, part of which could be used to support my thesis. Included in their population were individuals who were considered “hoarders”. This supported my interest in gaining valuable research skills while providing me the opportunity to “cross to the other side”. The concept of hoarding offered the perfect challenge of being viewed both as a social construct and a medical construct, especially with its recent addition to the DSM.

## Setting

The setting for this case study is the Sudbury & District Health Unit. Although it is headquartered in Sudbury, Ontario it serves both a rural and urban population spread over 46,550 square kilometers extending from Chapleau in the northwest to South Baymouth on Manitoulin Island in the south and French River to the east as seen in Figure 1 (Sudbury & District Health Unit, 2015). According to the SDHU (2015) it provides services to over 200,000 people, 82% of whom live in the city of Greater Sudbury.

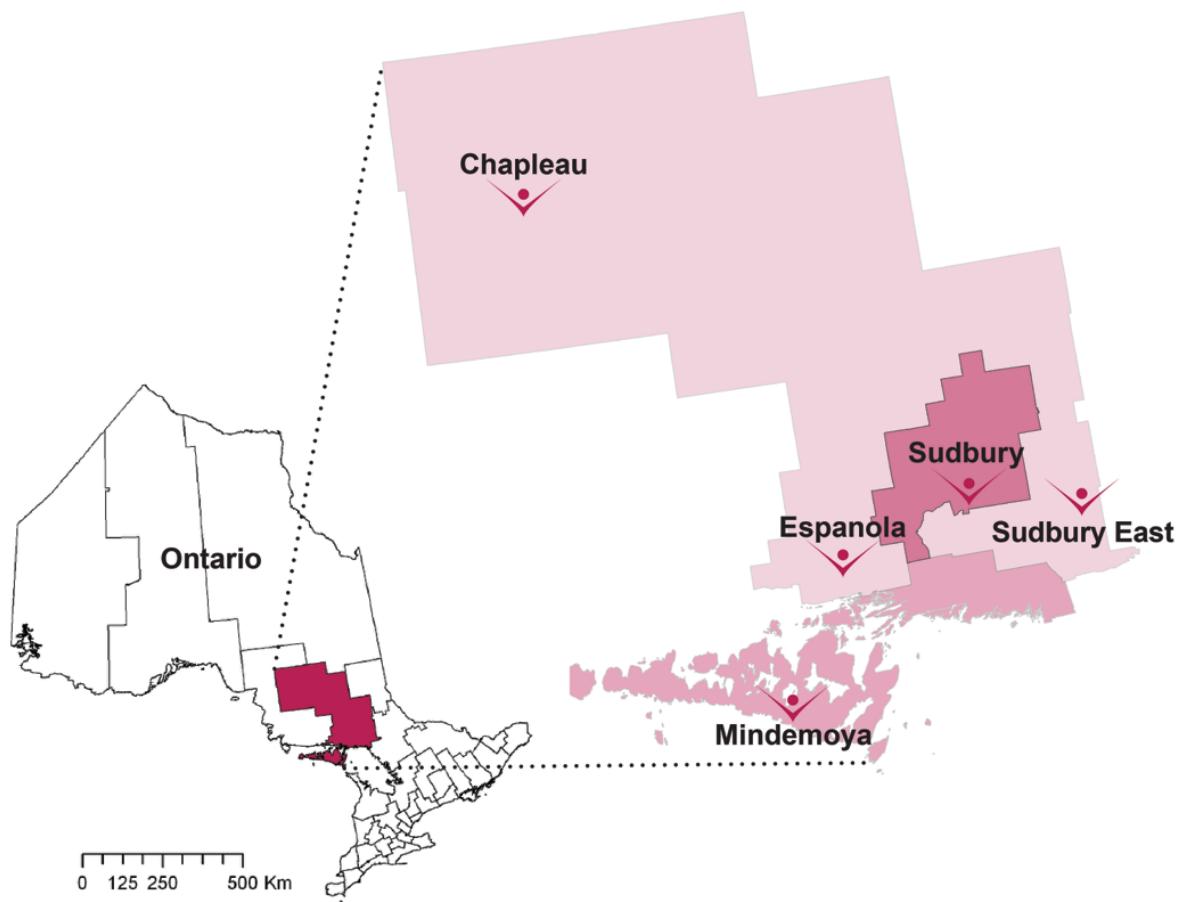


Figure 1

*Catchment Area of the Sudbury and District Health Unit*

Permission was granted for access to this setting though Dr. Suzanne Lemieux, Manager of Research, Evaluation, and Knowledge Exchange; Resources, Research, Evaluation and

Development Division, of the Sudbury & District Health Unit (through an agreement with the SDHU). As this research was conducted within a larger study conducted by Suzanne Lemieux, Sudbury & District Health Unit, and Phyllis Montgomery, School of Nursing, Laurentian University, ethics applications were filed by them and granted to them by both the SDHU ethics review board (Appendix A) and Laurentian University's Research Ethics Board (Appendix B). The ethics applications include provision for Laurentian University students to work on this project. Since the research for this study did not deviate from the protocol for the larger study but only conducted as a subset, no further applications to the ethics review boards were required.

## **Participants**

The population of concern comprised individuals referred to the Environmental Health Division of the SDHU for response to housing related health hazards that exhibited hoarding behaviours and any individuals involved in the case such as the PHIs, referral sources, and other agencies. In a period from 2013 to 2015, there were 40 such cases. A specific type of purposive sampling known as stakeholder sampling was used for this study. According to Palys (2008), this type of sampling is especially useful in evaluation research and policy analysis. "This strategy involves identifying who the major stakeholders are who are involved in designing, giving, receiving, or administering the program or service being evaluated, and by who might otherwise be affected by it" (Palys, 2008, p. 697). One ongoing case was selected for detailed analysis. Although this case is not representative of all hoarding cases referred to the SDHU as it is much more severe than most, the case provided an excellent opportunity to examine the involvement of multiple community partners. It was initially proposed that two individual hoarding situations be examined, but the volume of data involved in the single case made this challenging and would have required a larger study. Creswell (2013) suggests that too many cases dilute the level of

detail available within each case due to limitations on the amount of data that can be collected within the study time frame and this suggestion was heeded.

Inclusion criteria for participation in the study were developed; the criteria include those individuals who: 1) are willing and able to consent; 2) are over the age of 18; and 3) have received, within the last year, services in relation to a perceived condition of housing health hazard, notably hoarding; or 4) are PHIs who have provided, in the last year, services in relation to a perceived condition of housing health hazard; or 5) are individuals that have referred cases of potential housing health hazards to the Environmental Health Division of the SDHU within the last year; or 6) are employees of agencies who have worked with individuals who exhibit hoarding behaviour; or 7) are family members of an individual who has received services related to hoarding.

### **Data collection**

Data collection, as prescribed for case study research, included multiple formats (Creswell, 2013). The following data sources were utilized:

- 1) Document collection included public health inspectors' notes and photographs of the hoarding situation for David<sup>1</sup>—the individual at the center of the case study—as well as correspondence relating to this case. In addition, anonymized cases seen by PHIs at the SDHU over the last three years were analyzed for descriptive data to better understand the type of referrals received. Policies, procedures, and legislation in reference to health unit responsibilities for housing health hazards were also collected.
- 2) Individual semi-structured interviews were held in the field with identified stakeholders including the individual referred to the Environmental Health Division, the PHI involved in that case, PHIs involved in other hoarding cases, the referral source, other involved

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<sup>1</sup> David is not his real name. It is a pseudonym used to ensure confidentiality.

agencies, and family members. These interviews were conducted face-to-face. Prior to beginning the interview process, all participants received a verbal and written description of the purpose of the study and their involvement and were advised of their right to discontinue participation at any point throughout the interview. They were then asked to provide written consent. All interviews with David and his family members, as well as interviews with service providers, were audio-recorded and transcribed verbatim. Questions were related to the referral process, the inspection, the hoarding behaviour, the results of the inspections, and barriers and facilitators to the process as well as any suggestions for improvements to the process of remediating housing hazards. The interview guides are listed in Appendix C. David and his family members were provided with a \$20 honorarium to recognize their time commitment to the research. Although it has been anticipated, based upon the existing literature, that the individual exhibiting hoarding behaviour would be difficult to engage and that much effort would be required to build rapport (Lauder, Anderson, Barclay, 2005; Whitfield et al., 2012; Brown & Pain, 2014; Lauder, Roxburgh, Harris, & Law, 2009), this proved not to be the case. Because a strong rapport had been created with David by the PHI who had been involved with him for many years, David was open to participation and forthcoming. Although it was hoped that follow-up interviews with David could be conducted so that emerging themes could be further explored, he suffered a stroke which affected the part of the brain controlling speech so this was not possible.

- 3) Observations in the field were used to document the condition of David's home.

Observations of the interaction of PHIs with other clients were also used to facilitate

understanding of the relationship between PHIs and new clients. Written notes of observations were compiled immediately after the conclusion of the interviews.

Field notes were kept throughout the research process from the initial research proposal and literature review through to the completion of the thesis. These notes included logistics about how the literature search was conducted, hunches about possible emerging themes, and how themes were ultimately combined. The notes also included any difficulties encountered throughout the research process and any thoughts and feelings aroused in me while conducting research with this vulnerable group. This was considered most important as many authors have described the difficulties workers experience when providing services to this group (Lauder et al., 2005; Doron, Band-Winterstein, & Naim, 2013; Bratiotis, 2013).

### **Data Analysis Procedures**

Document analysis was completed prior to interviews with service providers and public health inspectors. This allowed for the determination of the most common referral sources as well as the construction of a list of PHIs who had the most experience with hoarding cases. Based upon this analysis, four public health inspectors were chosen to be interviewed and three agencies were selected. Many more agencies could have been included but time did not permit the inclusion of all possible agencies. All interviews were audio recorded and transcribed verbatim.

Because there is no specific code for hoarding in the records of the PHIs, all 94 referrals to the health unit that were coded as “housing health hazards” with “marginalized” users were examined to determine which of the cases involved hoarding. This was difficult as the word “hoarding” was rarely used by the PHIs. It was more common to read about the amount of clutter or the lack of pathways. From these records, information was extracted about the date of referral,

date of closure, inspector attending, complainant, number of entries, number of contacts, age, gender, medical concerns, and service agencies involved. It was not until interviews with three public health inspectors were completed that the hoarding cases were separated from all other potential hazardous housing situations. When the PHIs were interviewed, they were shown a copy of the Clutter Image Rating as designed by Steketee and Frost (2007). This is a scale which includes photographs of a bedroom, kitchen, and living room in increasing stages of clutter. Photographs are labeled from one to nine. I asked the PHIs to show me pictures from the index that were comparable to the words that they used when recording what they saw in the homes they inspected. A clutter index level of between four and five was deemed to be severe enough for inclusion as a hoarding case. For the PHIs this was often referred to as “minimal clutter”. If pathways were mentioned as being limited in any way, the case was considered to be a hoarding case. Forty of the 94 records were deemed to involve hoarding.

Analysis began with the 40 documented cases considered to be hoarding. Initially, this collection was read in its entirety to get a sense of the case. Beginning with the second read through, initial codes were assigned to text segments and, ultimately, these codes were combined to represent themes. Four records were coded and assembled into preliminary themes by another member of the team. These were compared and any discrepancies were rectified. As they became available, data from observations in the field and transcripts of interviews were coded. Additional themes were constructed based upon the differing points of view. In the final analysis of the case as a whole, all potential themes were merged into four broad themes, with subthemes in three of the four. The themes chosen were client characteristics, built environment, agency factors, and proposed solutions.

### **Strategies for Validating Findings**

Creswell (2014) suggests multiple ways to validate findings in a qualitative study and many of them were utilized. It is important that there be prolonged engagement in the field. Multiple interviews were conducted and three inspections of the home in which hoarding was present were completed. Additionally, I accompanied multiple PHIs on their inspections to observe their interaction with their clients. Triangulation of data sources is a relevant concept in a case study where multiple sources and types of data are used. Triangulation occurred between the documented reports of the public health inspectors, information provided by David and his family, information provided through interviews with PHIs and agency personnel, and through my own observations in the field. This written report provides rich descriptions, often in the words of the participants. Throughout the process of analysis, an audit trail was maintained which provided the rationale for any decisions made.

Bracketing has been suggested by Tufford and Newman (2010) to be a validation technique whereby the researcher sets aside her biases, preconceived notions, and personal experiences with the goal of listening to the participant's description of a phenomenon with an open mind. I have attempted throughout to bracket myself to the best of my ability. Having said that, I know that it is impossible to completely bracket personal perspectives and, for this reason, I have provided the reader with information about my background and social position so that he or she will be able to evaluate the extent that research bias may have been inadvertently included in this report.

### **Ethics**

This research is part of a study being conducted by the SDHU and Laurentian University and is included in the applications approved by both the SDHU ethics review board as well as

the Research Ethics Board at Laurentian University. This researcher has complied with all requirements specified in these applications.

When participants were contacted it was made clear to them that they did not have to agree to participate and either agreement or refusal would have no bearing upon any future services received from the SDHU. Potential participants were told about the purpose of the study and the nature of their participation prior to obtaining informed consent. The participants were also informed about how the information gathered in this study would be used. All data was anonymized prior to use. It is anticipated that the data used in the preparation of this thesis will also be the basis for an article for publication in a peer reviewed journal, presentation at an academic conference, and presentation to the stakeholders. Individuals who agreed to participate were told that they could withdraw from the study at any time. It is understood that one of the participants in this study is part of a vulnerable population. Although PHI participation in this study was supported by the management of the Environmental Health Division of the SDHU, the PHIs were told prior to their participation that management would not be made aware of which PHIs were interviewed for this study. All data was anonymized and no names of PHIs are present in this thesis. The only place the names of the PHIs appear is on their signed consents and these are in a locked cabinet with all of the other consents in the office of the manager of Research, Evaluation, and Knowledge Exchange at the SDHU, as indicated in the REB application. To protect the anonymity of the service providers and their organizations, the names of specific organizations do not appear in relation to the current research.

The data will remain the property of the SDHU and it will be stored by the health unit in a secure location for seven years at which time it will be appropriately disposed of. During the

analysis of the data, the information will be stored on a password protected computer kept in a secure location by this researcher.

It is important that the research was competently conducted and reported upon including multiple perspectives and any contradictory evidence. This researcher's personal biography accompanies this report so that bias can be evaluated. Every attempt was made to reduce any power differentials between participant and researcher. This included using appropriate language. The names used throughout this report are pseudonyms to protect the identity of the participant who hoards and his family. The designation PHI is used whenever information is presented that was collected from a PHI. Four PHIs provided interviews; they are not separately identified so that it is impossible to compile a profile for any one PHI. To protect the anonymity of the service providers and their organizations, the names of specific organizations do not appear in relation to the current research.

A final ethical consideration when discussing individuals who exhibit hoarding behaviour remained foremost in my mind. As long as these vulnerable individuals are competent and they are not in violation of any ordinances, they are free to live their lives as they see fit. It is incumbent upon me, as a researcher, to respect this. The goal of this study is to determine what stands in the way of remedying health hazards in the home created by hoarding. It may be that often the barrier is the lack of a perceived problem. This must be respected.

## Results

### David's Story

At the centre of this case study is David, a seventy-six year old man, who lives alone but for the company of his dog, in the home in which he was raised. David lives in squalor surrounded by mounds of garbage and other items which now extend beyond the walls of his

house. David has long gray hair and is unshaven. When first encountered, his clothes were dirty and certain smells were evident—urine, feces, and other bodily odours. David's story follows.

David was one of four children born to Ukrainian parents around the time of the second world war. Two of the four siblings died before the age of one year. David's sister, Sally<sup>2</sup>, reports that the death of these two children caused their parents to be very protective of their remaining two children. Sally admits to being the favoured child; she could do nothing wrong and her brother could do nothing right in the eyes of their father. Sally expresses some feelings of guilt, even today, over the fact that her brother was treated less well. Sally says they were raised in poverty but her parents owned three houses, one in which they lived and two which were rented out. She says that she and her brother were not close but they did play together in the neighbourhood with all the other children. According to Sally, David's first experience with hoarding behaviour was in early adulthood when he began accumulating electronics with the hopes of repairing them. He did, in fact, have talent in this area as he assembled his parents' first television.

His early history is complex. David's parents owned two houses on the same street, renting one out. According to Sally, David's hoarding and eccentric behaviour escalated with the death of his father in 1967. Soon after the death of his father, David and his mother moved into the newer of the two houses. It had a bathroom and a laundry on the main floor which meant that his elderly mother did not have to go down to the basement multiple times a day. At some point, David's mother moved back to the older home. Sally says that her mother was afraid of David because he hunted and kept guns in the house, and their mother was afraid of the guns. A neighbour who had a close relationship with David said that his mother moved back to the older house because of David's hoarding. David visited his mother, sister and her family at the older

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<sup>2</sup> Sally is not her real name. It is a pseudonym used to ensure confidentiality.

home but no one was invited to visit him where he lived, perhaps because of the accumulation and messiness. Sally recalls memories of David from this period. He walked around with glasses held together with tape and a radio with earphones around his neck. She went to his house once to beckon him for dinner and she could see that his house was packed with a variety of goods but she says that it was not dirty. After his mother died in 1988, David moved back into the family home and has lived alone in the home for the last 28 years. He broke off contact with his only living sibling 30 years ago after she refused to loan him money. Sally believed that no one had visited David in his house for many years. Sally mentioned that she had telephoned him on a regular basis but he never answered the telephone and never returned her calls. She tried to visit him when she travelled to Sudbury from her home 300 kilometers away but was unable to see him as he would never answer a door knock.

David never maintained steady employment. He played saxophone in a band and was involved in the volunteer community, once as president of a local service organization. As he got older he kept more to himself although he maintained a good relationship with one of the neighbours who says that David was a very intelligent man who “just went downhill.” Five years prior to this study, David was referred to the health unit by a police officer who had occasion to be inside David’s home. The officer thought that David had a problem with hoarding and was concerned because the house smelled of urine. David had sores on his feet that the officer thought needed to be examined by a physician but David refused to go to the hospital. The police considered arresting David under the Mental Health Act but ultimately decided that he appeared to be mentally stable. One of the PHIs managed to convince David to show him the inside of the house after threatening to come back with a warrant if David did not cooperate. The inspector reported that it was the worst case of hoarding that he had ever seen but it was more than just

hoarding; the house was filthy. It was difficult even to find some of the rooms in the house. A set of stairs at the front of the house leading to the basement was completely buried and indistinguishable as a stairway. Access to the bedroom was totally blocked. There was no bathroom on the main floor. David had to use a toilet in the basement and the stairs were treacherous; they were narrow and partially covered with stored items. As a person in his seventies, David was having difficulty walking much less navigating the stairs. The toilet in the basement was not hooked up to water because the tank was broken. A plunger and a bucket of water drawn from the laundry tub were used to flush feces into the sewer. There was no shower or bathtub. The kitchen was unusable for cooking or food preparation. Various items were placed and stored everywhere, often to a depth of a metre or more. Pathways allowed some limited movement throughout the house. Dust and cobwebs were everywhere. David slept in an old office chair in the living room; he did not have a bed.

Municipal and health unit staff discussed the situation. The building inspector advised the PHI that he would issue an order under the building code for the interior of the home to be cleaned out. David was given five days to comply. When it was not cleaned, a cleaning company was hired to remove everything except for a few mementos and a few pieces of furniture from the house. This cleanout began just one week after the expiration of the order. At the time of the cleanout, a social worker from a local agency was present to help David through the trauma of watching the cleanout but David was convinced to go to the local hospital, to have a gastro-intestinal issue addressed. David was ultimately admitted to hospital for the period of the cleanout. A contractor was hired to install a bathroom which included a working toilet and shower in one of the rooms on the main floor. A hot water tank was installed as David had not had hot water in years. It was decided that the municipality would spearhead this clean-up with

the cost being added to David's taxes. When the work was complete, the house still appeared to be in rough shape, but it was clean. The yard was cleared out which satisfied the neighbours' concerns. To the surprise of all involved, David paid off the cost of the cleanup and renovations, reported to be more than \$25,000, as soon as the bill was delivered. Unfortunately, there was still concern that David would continue to collect goods, items and materials. Service providers continued to be involved. Within one month, the PHI noticed that the kitchen was becoming cluttered and that soon the new sink would not be accessible. The new shower was not being used as a shower as David was storing a mop and pails in it. The PHI was certain that the house would revert to its previous condition unless someone monitored David's scavenging and provided him with counselling. It was arranged for a worker to do this.

David continued to collect various items. He was somewhat mobile and was able to travel around town by walking and taking the bus. He often went to a drop-in centre that provides care to the vulnerable. David attended a clinic to have wounds on his legs bandaged. He had been told by a physician that washing his legs would aid in their healing but he did not believe this. He believed that healing would occur through the application of a blister paste. David did not shower at home as he used his shower for storage. The clinic ultimately arranged for David to shower there because his body odour was very strong; indeed, it had become necessary to devote one room of the clinic to him alone and they needed that space to serve others.

As David's mobility declined, he acquired an electric scooter which made it easier for him to scavenge. He attached baby strollers to his scooter which allowed him to transport smaller items to his home. He also managed to find a trolley that he dragged behind the electric scooter when he wanted to transport larger items. It became known in the neighbourhood that David was willing to take items no longer wanted by their owners. Consequently, people dropped off

various items into his yard. He was amassing clutter both inside and outside his house. The municipality was soon notified again of the accumulation of items outside the home. The mail carriers refused to go to his home because the yard and the walkway leading to the mailbox were covered with dog feces. David made arrangements for mail pickup at the distribution centre close by.

The health unit received another call, less than four years after the cleanout, from first responders. David had been transported to the hospital by ambulance and the paramedics were concerned about the state of the house. Whenever paramedics encounter a situation that either placed them in danger or increased the likelihood that an older adult will require readmission to hospital in the near future due to their living condition, the supervisor is called upon to investigate further. In this case, the paramedics were also concerned about the safety of a dog on the premises which necessitated a call to animal control. As a result of the call from the first responders, the PHI involved in the original cleanout attended at the hospital with a book of photographs of David's home that had been taken prior to the first cleanout. The hope of the PHI was that he could convince the emergency room physician to order a mental health assessment for David. However, David declined the assessment and left the hospital. He could not be held under the Mental Health Act because he was deemed competent. He agreed to attend a future appointment with a geriatrician but hospital staff members were doubtful that David would attend.

The yard was in a mess and the municipality had been called in to have it cleaned up. The PHI knew that this would be a traumatic time for David so he attended the clean-up, and brought a cup of coffee for David. Even though the PHI was the same one as had been involved in the clean-up four years prior, the relationship was solid; rapport had been established and there was a

relationship of trust. David welcomed the company. While on the property, the PHI asked to be allowed to see the inside of the house. It was clear that David was embarrassed by the state of his home but he allowed the impromptu inspection. Although deemed not to be as bad as it had been prior to the first clean-out, the results of David's hoarding behaviour had taken over the inside of the home again. Piles were close to a metre high with only small pathways for walking between them. This was not a healthy environment for anyone and his home environment was likely contributing to David's ill health. David was asked at this time if he would like to participate in an SDHU study of housing health hazards being investigated by the PHIs and he provided consent. The interview was planned for a later date.

Another admission to hospital, only weeks after the yard cleanup, prompted another call to the health unit inspection staff, this time by the hospital social worker. David's health was deteriorating. He had sores on his legs that would not heal. He was supposed to attend a clinic to have the bandages changed once a week; however, David had not attended his appointments, or, at times, the nurse was not present or did not bring supplies with her for the dressing change. Consequently, care was infrequent and the sores on his legs were not getting better. A local organization that had been engaged to provide care had not been sending staff to David's home to dress his wounds for years because it felt that the environment was not safe for their workers. David's diabetes was out of control which may also have been contributing to his poor wound healing.

David was interviewed for this study while in the hospital because an interview in his home would have been intolerable for any interviewer, due to the strong odours (fetid environment). It was reported that two first responders attending David's house recently had to exit the house to vomit due to the overpowering smell. When asked about the clutter, David

claimed that the installation of shelving would solve his problem with clutter. He also said that he needed to clean up the inside of his home so that he could get his scooter inside. David had spoken with a mental health worker about securing funding for the construction of a ramp. He also mentioned that his home needed rewiring and additional insulation to help to keep it warmer. However, David considered the costs to be prohibitive. In his view, no other work on the home was required to remedy his situation. When asked about the need for additional support services, David requested none.

With no alternative living arrangements available, David was sent back to his unsanitary home after a short stay in the hospital. It was clear that something had to be done to improve the situation at home. The PHI worked tirelessly on David's case, bringing community partners together in an attempt to remedy the situation. A meeting was convened by the inspectors of the SDHU subsequent to David's discharge from hospital; those attending the meeting were individuals from by-law, building services, health services, and first responders. Members of these organizations had all been involved at some point in David's case. This was an attempt to remedy the situation for David, but it was also an attempt to find solutions for other clients in a similar predicament. A case was made that the situation was one of extreme danger, both for David and for community workers entering into the home. It was decided that the best strategy for moving forward was to complete a mental health assessment in the home so that the assessor could see David in his own environment. It is questionable whether or not David would have complied since he had already rejected this option in hospital. No other directives were forthcoming.

Two months after his previous admission, David was again admitted to hospital. Staff at a medical clinic had suggested that David go to the emergency department to have a swollen hand

examined. On his scooter, David was able to make the three kilometer trip to the hospital, perhaps aided by mild winter weather and a lack of snow. While at the hospital, David suffered a stroke in the area of the brain controlling speech. Because of his frequent hospital visits for increasingly severe conditions, it was becoming clear that David could not return to his unsanitary home. The PHI involved in his case visited David in the hospital, first just as a friendly visitor, and, then a second time, after the weather turned cold, as a concerned service provider. Because of the lack of heat in the house the inspector was worried about the possibility of frozen, leaking pipes and volunteered to go to the house to investigate.

A visit to the house confirmed that the pipes had frozen and burst and water was pouring down into the basement. Upstairs, an even greater buildup of possessions was evident compared to the PHI's visit four months prior. Piles of goods were evident throughout the house, often to a depth of a metre or more, and the pathways were becoming narrower. There was no organization to the piles and much of it appeared to be garbage. It was observed that the piles included old plastic bags, plastic containers, and plastic coolers, tools, toolboxes, and old transistor radios. Paper was strewn about, much of it shredded, perhaps by mice. There was little furniture in the house. The only accessible piece of furniture was an office chair that functioned as a place to sit as well as a bed. An open umbrella blocked the chair from the view of passersby on the street. A laptop computer was placed in front of the chair with a newer model monitor nearby. The kitchen was unusable. No one could reach the stove, refrigerator, or sink.

Three blenders were accessible and all contained dried residue. One cupboard was open and a few cans were visible. Large pails of a dark liquid had frozen and they blocked much of the kitchen. A precariously placed microwave oven was accessible and may have been functional. No edible food was visible.

The bathroom was filthy. The toilet had four seats stacked one on top of another, joined with duct tape. It appeared that the toilet was blocked as it was filled with feces and there were feces smeared all around the toilet. The shower contained cleaning supplies and there were more cleaning supplies, dish soap, Lysol®, and scrub brushes scattered about the bathroom. The sink was barely accessible as there was a pile of goods in front of it.

No clothes were visible except for some jackets on hooks at the front door. An assortment of articles remained outside—items that had been amassed since the municipality had cleared the yard out four months earlier. Two strollers were visible and these contained the only food found at the house. Potato chips, bread, and oranges were stored in the baskets underneath. There was also a collection of electronics, bicycles, cabinets, and an old scooter around the perimeter of the house. A trolley lying close to the street may have provided David with the means to transport items he found to his home. It had become clear that some decisions had to be made.

The PHI called the fire service, the building inspector, and David's caseworker from the medical clinic. They held discussions about cleaning out the home, just as had happened four years prior. David had made it clear that he planned on returning home from the hospital. Ultimately, because of the burst pipes, the group decided that the building inspector would post a notice stating that the home was "unsafe for human habitation". It was now a certainty that alternate living arrangements had to be secured for David when he was discharged from hospital. When presented with the fact that he would not be allowed to go home, David began to contemplate a move to a long term care facility.

David's sister, Sally, had been called after his stroke and she came from out of town to visit. David signed a "Power of Attorney for Personal Care" document naming Sally responsible in case he was not able to handle his affairs in the future. Although David made it clear to his

sister the first time he saw her after his stroke that he intended to return home, by her second trip he was already contemplating a placement in long term care. The social worker at the hospital began to make inquiries and applications were to be completed by David and his sister. Sally credits the PHI for convincing David to consider going into long term care. While Sally was in town she was shown the inside of her family home prior to its boarding up. She was not prepared for the devastation that she witnessed. David had given her a list of things he wanted from the home such as photographs, scrapbooks, and radios. The PHI had previously brought David his laptop computer. The dog had been removed by animal control. Sally stated that she was glad that David would not be permitted to return home.

The PHI involved with David commented that he was not trained to respond to this type of call but stated that he had learned a great deal about relationship building in a previous career; he attributed this work experience to his success in being able to get into the homes of individuals exhibiting hoarding behaviours. The PHI expressed a belief that he is providing services normally delivered by a social worker but he feels a responsibility to vulnerable members of the community. Although one PHI provided most of the services to David and other vulnerable individuals with housing health hazards, this PHI involved his co-workers in the investigation and planning for alternative arrangements for this client. By mentoring other PHIs, it was hoped that they would learn how to better serve the vulnerable population. It is unknown how many contacts the PHI on this case made with David, his family, social service agencies, police, fire, and hospital but it is estimated that the number was more than one hundred and the time spent was likely not measured in hours or days, but weeks.

### **Document Analysis**

This case study involved David and his interactions with PHIs. It also included social service agencies that, over time, have been involved with David. Interviews were conducted with some of the PHIs as well as with service providers. Observations in the field were also included as data. Legislation governing the role of the PHI was examined. As David is only one of many hoarding clients that are served by the SDHU, records for the previous three years were analyzed to gather information about the other clients served. Key concepts were extracted from the records to describe characteristics of the clients and their interactions with PHIs.

Public health inspector records for all cases entered into their “Hedgehog” database as “housing health hazards” in “marginalized populations” for the years 2013 to 2015 were examined. It was difficult to know which cases to consider as demonstrating hoarding behaviour from the records as these records were the personal case notes of the inspectors involved and they did not use a consistent system for recording these inspections. I interviewed three public health inspectors and asked them, using the Clutter Image Rating devised by Steketee and Frost (2007), to show me what they meant by “minimal clutter”, “clutter”, “hoarding” and “pathways”. This scale shows pictures with increasing levels of clutter in a kitchen, bedroom, and living room. Steketee and Frost considered that anything at a level four or beyond on a likert scale from one to nine to be indicative of hoarding behaviour. Any time that pathways were mentioned, the inspectors indicated that they considered this at a level five or above. Even “minimal clutter” was scored as a four by the inspectors. From this information, I was able to separate out 40 records from the 94 as homes that were cluttered enough to be included in this analysis, 15 of which were considered to be severe, as seen in Figure 2.

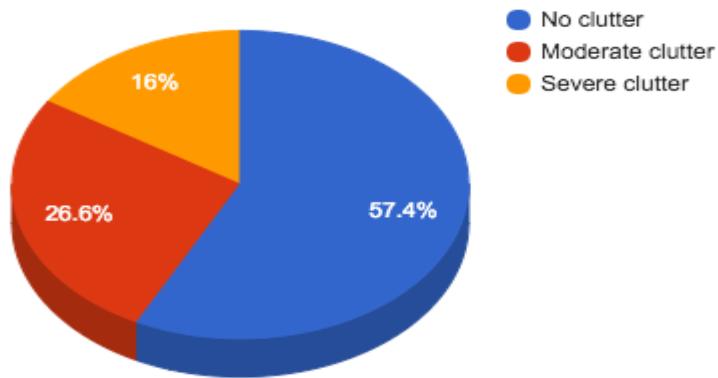


Figure 2

*Extent of Clutter in Homes Considered in the Hoarding Designation (n=40)*

Nearly 25% of the residents were previously known to the SDHU Environmental Health Division. Within the 40 records indicating cluttered residences, living situations, as seen in Table 1, were as follows: 28 individuals lived alone, three as married couples, two as couples with adult children, five parent/adult/child households, and one parent/teen household.

Table 1

*Living Situations for Individuals Living in Clutter (n=40)*

Living Situation	Number of Cases
Alone	28
Married Couple	3
Couple with Adult Children	2
Parent with Adult Child	5
Parent with Teen	1

Residents were evenly divided between men and women. The age of the residents was not always recorded by the PHIs but the age of the residents listed ranged from 16 (living with a parent) to 88. Twelve of the records indicated that the resident was “elderly”. Only three were under the age of 50 and 11 were under the age of 65. Referrals most commonly were received from the owner or landlord of the unit where the individual(s) resided, with 17 of the 40 received from this source. First responders referred another eight. Health care providers referred 12. One resident self-referred and two referrals were called in by concerned citizens. Referral sources are shown in Table 2.

Table 2  
*SDHU Referral Sources for Hoarding (n=40)*

Referral Source	Number of Referrals
Owner	17
Health Care Providers	12
First Responders	8
Concerned Citizens	2
Self-referral	1

Three quarters of the reports indicated that the resident had physical limitations, poor physical or mental health, or was awaiting long term care placement. In 31 of the records PHIs discussed community support for these individuals. Residents were equally divided between having informal supports (family, friends, and neighbours) and formal supports (social services). Three of the residents were listed as having both formal and informal supports and two were noted to have refused support.

Resolution of these cases was notable. In only nine cases did the PHI describe satisfactory resolution of the case. Three of the referrals had been exaggerated and required no intervention and one inspection was for administrative reasons only and did not require intervention. In five cases, the residents moved out of their accommodations and one resident died during the period of investigation. One case remained open. Half of the PHI records showed no resolution of clutter in the reported cases with reasons listed such as “[d]ue to the fact that the tenant doesn’t want me to re-attend, clutter is not overwhelming, the writer believes no further health unit action can be taken on this matter;” or “[s]o basically, although not pretty, not really a health hazard the health unit can deal with;” or “[t]he property manager was contacted and advised to follow up with the fire department.” Resolution of the cases is shown in Table 3.

Table 3

*Resolution of Hoarding Cases by the SDHU (n=40)*

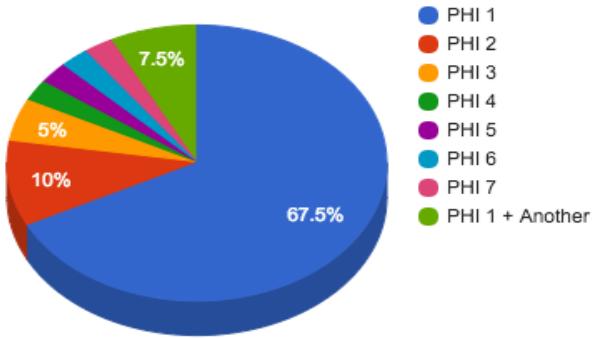
Resolution	Number of Cases
No Intervention Required	3
Administrative	1
Satisfactory Resolution	9
Resident Moved	5
Resident Deceased	1
Open Case	1
Unresolved/Partial Resolution	20

The PHIs involved worked hard to remedy these cases. There was an average of 7.7 contacts for each case with a range from two to 27. These contacts included other PHIs, property managers, police, fire services, hospital staff, paramedics, by-law enforcement, home care

agencies, animal control, family, friends, and neighbours. Many were contacted more than once. The number of contacts is likely underestimated. Given my observations of the PHIs in action, it was notable that often many contacts were not recorded. For the 32 cases that listed outside agency involvement, the average number of agencies contacted was 2.25 per investigation.

Reasons for the referrals were listed on each document: “house disrepair/sanitation” (38), “garbage” (4), “odours/animal excrement” (3), “flooding” (2), “rodents/vermin” (2), “insects/cockroaches/birds” (1) and “other” (3). Some cases listed more than one reason for referral. Most cases listed only “house disrepair/sanitation” when it was clear from the reports that there were often multiple issues. From thoroughly reading through the records, the motivation for the referrals was surmised. These varied from a property manager attempting to have the tenants clean up, initiation of eviction by the landlord, the hospital checking on the safety of the home prior to patient discharge, concerned citizens checking on friends and a report for an insurance company. As some cases were exaggerated, the motivation of the complainant, at times, appeared to be vindictive.

It is worth noting that all of the inspections were completed within the City of Greater Sudbury even though 20% of the population within the SDHU catchment area resides outside the city. The cases were evenly divided between years with 2013 and 2015 seeing 14 cases each and 2014 seeing 12. One PHI responded to 30 cases, three of which were with another inspector. In the remaining cases, one PHI responded to four, one responded to two, and four responded to one case each. Case division is shown in Figure 3.



**Figure 3**  
*Division of Cases between Public Health Inspectors (n=40)*

### Thematic Analysis

All interviews with the client, his family, PHIs, and service providers were transcribed and they, along with the records of other cases, were coded in the process of collecting emerging themes. Four themes involving nine subthemes were found within the data. The themes include client characteristics, built environment, agency factors and proposed solutions. Client factors are divided into the subthemes lack of social support, noncompliance/independence, infirmity, self-neglect, and crisis. Environmental factors include unsanitary and unsafe conditions and agency factors include mandate and lack of options. Each will be discussed below. Proposed solutions were all agency-related factors. A conceptual framework showing the interrelation of these themes can be seen in Figure 3.



Figure 3  
*Schematic Diagram of Themes*

#### **Client characteristics.**

Client Characteristics have been divided into five subthemes: lack of social support, infirmity, crisis, non-compliance/independence, and self-neglect.

#### ***Lack of social supports.***

David lived alone and was estranged from his only living sibling. In the past, he had been involved with service organizations but not for many years. David's friends no longer visited as the condition of the home likely deterred them. David maintained contact with only one neighbouring family with whom he interacted outside of his home. The mother of this family provided meals at times to David and her adult son kept a close eye on the house. In fact, this neighbour took it upon himself to protect David. Any time a service provider came around, this neighbour went over and questioned the visitor. He believed that people should be allowed to live as they see fit and told people who he perceived to be bothering David to leave him alone. No one helped with the cleaning and laundry and no one went to the house to bandage his ulcerated legs. A home care agency had stopped going to the houses years before due to the

safety hazard. David had used the services at the drop-in centre for years but he was shunned by the patrons of the soup kitchen. One of the workers spoke about David's social rejection.

He doesn't have water in his home to shower; he doesn't shower. So he is getting a lot of flak from the soup kitchen and mission downstairs...the clients complain about him, about him, to him. They say nasty things to him. So I think he has stopped coming because he doesn't want the abuse, the verbal abuse.

### ***Infirmity.***

David is 76 years old. He has difficulty walking and now uses an electric scooter. His diabetes is poorly controlled and he is incontinent. David mentioned that he sees a "heart doctor" and most recently he had a stroke that left him unable to speak, although his speech is slowly returning. It is the condition of his legs that bothers him the most. David has been having difficulty with his legs for fifteen years, ever since he "crashed with diabetes". The ulcers on his legs are often infected and David has been warned in the past that he may require amputation of some of his toes in the future. He has difficulty getting medical care for his legs when he wants it or requires it. A home care agency that previously worked with David will no longer come to his house to bandage his ulcers so David made arrangements to meet a nurse at a drop-in centre but these arrangements seemed to have fallen through many times. Consequently, his legs often become infected. He gets frustrated with the lack of care and concern for his condition. He describes one of his more recent encounters:

For the past month, then up on the hill I had an appointment for seven o'clock to get my legs wrapped. I go there and they said there is nobody there to do it. That's at the [agency], you know...The receptionist looks at the screen and says, "Go to the [drop-in centre]." At seven o'clock there is nobody there. It closes. By three everything is shut

down. You need an appointment. I can't get through to her. I need attention now because I got pain, I got oozing and infection. Finally, I got loud, all of a sudden, up, a worker says, "I can do it." So all along they said they couldn't do it, they couldn't do it, now they do it. This has happened on a number of occasions.

Many infirmities were mentioned within the 40 documented cases including recent surgery, fibromyalgia, diabetes, cancer, incontinence, arthritis, substance misuse, frailty, recent heart attack, mental illness, and being confined to a wheelchair. Some form of mental illness was mentioned in more than 25% of the charts and, in some cases, it was the reason for referral. In addition, the majority of the clients listed in the documented cases were over the age of 65, which potentially, for some, may have been associated with age-related issues such as a decline in cognitive abilities.

There were concerns that individuals with no mental health diagnosis, who appeared competent when away from their home environment, were not actually able to care for themselves. One of the participants from a social service agency expressed her concerns about this:

Sometimes they were capable of being able to answer their name, the date and where they were. So they would get the 'all clear' from the emerge department, being mentally competent. And yet, though, we would see their living conditions and I would say, "How can they say that they are competent to care for self?" ...So I would say, let's have somebody like [name] who does the provincial competency testing, come and test them here, where we see them. To have them once during the hospital and they have been cleaned up and their filthy clothes are taken off and they are put in a hospital gown and they are washed and they are in a hospital bed...they are able to answer questions and

they can maybe even use a laptop but when they are back in their living conditions, don't tell me that they are competent and they aren't, you know, a risk to themselves.

***Crisis.***

It was evident in David's case, as well as in the other 40 documented cases, that clients come to the attention of the SDHU when they are in crisis. Of the 40 records, half were referred by first responders or health services. The reasons for involvement of the emergency personnel included a sudden death, suicide attempt, mental health breakdown, and need for transport to the hospital. Seventeen of the remaining 20 were referred by the landlord or his/her agent. In these cases, the landlord was often taking the first step toward eviction, thereby putting some of the clients at risk for homelessness. David had been admitted to hospital three times between July and December of the same year, each admission for an increasingly more severe ailment than the previous. It was rare for an individual with hoarding behaviour to come to the attention of the SDHU who was not in crisis. Examples from the presenting "issue" section of three of the 40 records clearly demonstrate that crisis precipitated the referral:

- Caller is Detective Constable [name] [police service]. They had attended at the subject unit [address] on a sudden death call and found the conditions appalling in the unit. The wife of the deceased is presently at [name] hospital and there were some issues with the son's mental health.
- Landlord concerned about the living conditions of tenant [name], 80 years old, residing in [address]. Infested with mice and issue hard to deal with due to his clutter. Also incontinent and unit smells of urine. Tenant presently at [hospital]. Landlord willing to help with cleanup but tenant is stubborn and has chased away cleaners before.

- Complainant is manager, maintenance at [a not for profit apartment building]. The tenant of [name] has bedbugs. The unit has a presence of hoarding, and so attempts to treat the unit for bedbugs have failed. The tenant is 88 years of age, and the manager does not want to evict the tenant. The unit needs to be cleared of clutter for successful bedbug treatment to proceed. Manager is asking for assistance with either 1) convincing tenant to clear unit or 2) convincing the tenant to allow the manager to arrange for the removal of hoarded belongings.

***Non-compliance/independence.***

Although non-compliance and independence seem like two very different constructs, they actually appeared to fit together well in these cases for it appeared that the non-compliant behaviour was in aid of asserting independence. For example, David has been told to take showers because it would help his legs heal but he does not shower. He makes appointments to have his legs dressed at the clinic and does not attend. Even though his house is not fit for human habitation according to the public health inspectors, David states that he wants to return home after discharge from the hospital as he is “comfortable” at home. Even though it is clear to everyone who enters David’s house that he cannot perform activities of daily living, he asserts that he can:

I try to stay healthy and do things for myself and when I can, like you wouldn’t know it, but before I crashed I have done a lot of cleaning inside and out. So if I am healthy I can do most of the work for myself inside the home, do my own shopping, do my own washing. I put clothes on my scooter and take it to the wash and dry because with the bus I got to walk...When I am healthy, I feel like a king. Nobody to bug me.

Other clients, as noted on the PHI records, have also asserted their independence. They refused to go to the hospital when someone called for an ambulance on their behalf. They refused services to remedy their situation. They resisted attempts by social services to move them into long term care facilities. They refused to clean up as recommended by the PHIs, even when they were physically capable of doing so.

One documented case clearly demonstrated the noncompliance/independence situation of one woman, likely in her seventies, living with two adult sons who were close to 50 years of age. One of her sons was admitted to hospital and a home care agency reported the poor living conditions to the SDHU. The home had been visited two years prior but the PHI was not allowed in to confirm clean-up at that time. The son called his living conditions “terrible” saying that the house had not been vacuumed in 15 years. The PHI found much clutter but no garbage. A couch was blocking the back door and the dining room was not accessible at all. The kitchen was very crowded as a dryer and stove were pulled out into the middle of the floor. The stove had not been plugged in for 10 years because it belonged to an ex-husband. The kitchen sink was plugged and no amount of plunging would clear it. The mother was eligible for Canada Pension but would not apply. The PHI encouraged this but to no avail. After four months she still had not applied and the sink was never unplugged because they could not afford a plumber. The son, who had been in the hospital for complications of diabetes, ultimately began to slowly clean the house and move the furniture to make more space and increase safety.

***Self-neglect.***

David has been described as filthy, with very dirty clothes. He admitted that he needed to wash them. He does not care for his ulcerated legs and he does not monitor his diabetes which results in him being admitted to hospital. David reported that he had lost over 200 pounds in the last 15 years. Since he is not very mobile, it is likely that David's inability to prepare food is responsible for the weight loss. He knows that he smells but nevertheless refuses to take a shower most of the time. There was no shower in his home until after the cleanout and renovations four years prior to the study and now that shower is used for storage. Occasionally David is convinced to take a shower when he is at the drop-in centre. Instead of showering to remove the smell and laundering his clothes he talks of suing people who deny him services because of his odour. David says,

All along people have been telling me that my odour is health related, incontinence, that's a health problem. I empty at home, by the time I get here, downtown, I fill my diaper. People can smell it. When these things ooze, the feet ooze, they can smell that. At first, the medical profession told me to wash my feet and the problem will go away. I had done that for years, thousands of dollars, and finally a nurse says blister paste should work. I thought it was something new. It goes back to the 80's. The oozing stops, the feet start curing up. Then, now I am told to take a shower and change your clothes and the smell will go away. It doesn't. I have got a peculiar smell; some people smell it and some people don't. I get on the bus; the bus driver is friendly. And I get on the next bus and he says, "You reek". I get to the clinic and I say, "Do I reek or smell?" He said, "No. Maybe just a little bit." So I have got a class action suit going. The same medical people

which told me that this is a medical problem won't sign to it. They won't give me a letter that says, "Your odour is because of your incontinence and your lesions."

Within the documented cases, it is more difficult to find examples of self-neglect than it is of environmental issues because the focus of the inspectors is the housing situation. In some files, a few comments were made about clients smelling of urine or clients having very dirty clothes or not having done laundry in a long time; however, none were recorded as being as self-neglecting as David.

### **Built Environment.**

Built environment has been divided into two subthemes: unsafe and unsanitary.

#### ***Unsafe.***

David's home was not only unsafe for him but it was also unsafe for others entering. A home care agency had withdrawn its workers from the house years prior to the study. Prior to serving clients in their own homes, these workers assess the situation for potential danger. They are known not to service homes of individuals exhibiting hoarding behaviours. Another agency providing first response into homes is concerned about employees entering unsafe residences. Because the Occupational Health and Safety Act regulations governing first responders are different than those governing most workplaces, these employees cannot refuse to enter homes overtaken by hoarding. David's home was known as being dangerous to enter. Workers could only enter and exit in single file. Although David currently weighs between 200 and 250 pounds, he previously weighed over 400 pounds. Because of the lack of space in which the paramedics could work, they would have been in danger of injuring their backs when lifting him. If there had been a fire, movement around David's home would make it impossible for firefighters to work

effectively and safely, especially when disoriented by smoke. One first responder accurately portrays the multiple risks of hoarding for community workers.

And sometimes the amount of belongings they have put the structure at risk because they are having way too much weight for the floor joists and so it's compressed. And maybe even risk of spontaneous combustion because they may keep rags that are oil soaked and the food that is starting to rot, again can heat up. So there is plenty of things that can become fire hazard in itself, in addition to extension cords being used inappropriately. So these all present risks to responders. A lot of times these people end up having little trails in and out of their residence, then they have mobility issues, so if they fall and get hurt paramedics are expected to go in. Health care providers such as your private nursing companies and [home care agency] can say, "We are not going in until it's safe", but your emergency first responders, we have got limitations under the Occupational Health and Safety Act and we can't sit there and say, "Well, we are not going in." We are expected to go in and, if this person is collapsed and we need to do life saving measures or carry them out, it becomes treacherous, risk to be going through the clutter, around the clutter, through these narrow paths. You can't bring the stretcher or proper means of conveyance into these places. So you are putting paramedics' careers at risk because they only have one back and one bad lift could end their career.

Hoarded items were often located too close to the stove. The PHIs while on their inspections would sometimes unplug the stove or trip the breaker so that stoves could not be accidentally turned on and start a fire. In one case of hoarding where items were reported to be piled chest high, there was an oil filled space heater near the only available chair. This resident also had a cluttered stove and became argumentative when the fire inspector suggested that the

stove be unplugged. Because there were no health hazards, this case was managed by the fire inspector.

A call came in to the health unit in 2015 due to the living conditions of a tenant. It was a case that the fire inspector had dealt with in 2012. It took 10 minutes for the resident to clear access to the front door so that it could be opened. Baseboard heaters were covered with a metre high pile of bedding. Power bars and extension cords ran amidst clothing and other flammable items. There was clutter on and around the stove where one element was still being used. There was also a hot plate on the balcony. Although the fire inspector did not accompany the PHI on this call, the client was warned that the fire inspector would be calling and if he wasn't allowed access, a warrant would be sought to gain entry.

In one case, the apartment was crowded due to downsizing after a workplace accident left the resident on a disability pension. There was little room to navigate throughout the apartment and little access to the entranceway. The tenant would have had difficulty exiting quickly in an emergency. Storage bins were on the bed, couch, and in the shower. The apartment was not dirty but was still unsafe. The resident was slowly cleaning but had recent surgery and was having difficulty. He did not have a vehicle and he relied on charities to pick up donations. The property manager reported the case when it was detected on an annual inspection of the apartment. Because there was no health hazard, the PHI suggested that the property manager call the fire department if he wanted resolution. It was common for the PHI either to call the fire department or suggest that a property manager call the fire department for resolution as it was perceived to have more power.

***Unsanitary.***

There is no question that David's house is unsanitary. With mice scurrying about, sticky strips full of dead flies hanging from the ceiling, and cobwebs covered in dust, there is evidence of an abundance of animals, some of which may carry disease. There are feces smeared over the toilet seat and filling the toilet bowl; the toilet no longer flushes. David spoke of bottles in which he collects urine and that he does not always empty, and admits that they are likely causing quite a stink in his house. He says the reason there are flyers lining the indoor walkways is that they collect the urine he dribbles. There are dog feces lining the pathway into his home. Feces are another breeding ground for disease. David has nowhere to wash himself. The pathways to all sinks are blocked and the shower is used for storage. There is food decomposing in three blenders in the kitchen. There is no place to wash them so it is likely that he uses them in this state. His refrigerator is not working; there is no way to keep food at a safe temperature. It appears that no cleaning has been done in the four years since the health unit ordered a cleanout of the house. The house is very damp and there are signs of mould and mildew.

It was common in many of the hoarding situations to find litter boxes overflowing and cat or dog feces spread throughout the homes. Human feces staining furniture, carpets, and beds were often documented. Cockroaches were often seen. Mice droppings were commonly noted and in some cases it was evident that the residents had tamed the mice and made them into pets. Although more of a nuisance issue than a sanitation issue, bed bugs were a cause for concern in many cases. From the records, there was evidence that most property managers tried to keep bed bugs under control but they were hampered by the residents who hoard. To fumigate for bed bugs, all belongings must be moved away from the walls and this often does not happen. Bed bugs in these units continue to reinfect other units within the apartment building.

One tenant, a male in his thirties, had a most unsanitary home. It was cluttered but most of the recordings of the PHI centred on the lack of cleanliness. There was a large population of flies in his unit, including inside the refrigerator. Mouldy bread on top of the refrigerator was beginning to liquefy. The bathroom and kitchen were described as “filthy” even though a mop and cleaning supplies were observed. Piles of dirty laundry were evident and reportedly accumulating because the resident “doesn’t know where the laundromat is.” After eight months of monitoring there was little change. Because the resident was “young, mobile, mentally stable” choosing to live in a dirty, cluttered unit and because the condition of his apartment was not affecting other tenants, his case was closed. This individual chose not to engage with services.

One landlord was in a quandary because he had been ordered by by-law enforcement officers to remedy a rodent infestation. The tenant’s apartment had “piles of mice feces on the floors and furniture” and also on the stove, counters, and in the bedroom. The tenant was purposefully leaving food for the mice. There was also a heavy infestation of bedbugs to the point that the PHI recommended that all furnishings be discarded. Since the tenant was on the Ontario Disability Support Program (ODSP), the PHI made the call to the ODSP office on the client’s behalf enquiring about finances to replace bedding and furnishing. Hoarding was also an issue so it was difficult to rid the apartment of its infestations. The tenant was uncooperative with the clean-up as she didn’t want to throw anything away. Eviction proceedings were started so that the landlord could comply with the order from by-law enforcement. The tenant refused to leave. Ultimately, a worker from a drop-in centre accompanied her to a shelter so that the sheriff would not be called to remove her.

The situation can become even more desperate. An older adult, obviously ill, had been unable to keep up with her apartment and her animals. When first responders found her, she was

seriously ill and transported to the hospital. Her house was quite cluttered. The issue as recorded by the PHI is as follows:

[] from [first responders] called to inform the SDHU that an elderly woman had been brought into the hospital. Her living conditions were not suitable. As per [first responders] the house was dirty, and smelt horrible. The woman was found on the floor wearing only a T-shirt and was full of urine and feces. There were multiple dogs in the house and one dog was deceased and was decomposing. The flies were bad. The woman had fallen and could not get up. The call came in from a neighbour that had not seen the woman in a few days and was concerned. [First responder] stated that the woman probably only weighed 50 kg and that she stated she was on no meds and had no family. (After speaking with the nurse in E.D. it was noted that she had an aunt and cousin). The police were dealing with the dogs.

### **Agency factors.**

Agency factors have been divided into two subthemes: mandate and lack of options.

#### ***Mandate.***

The discussion about mandate is interesting because various interviewees had differing opinions on the topic. The health unit appears to be taking the lead in hoarding cases but the idea of a clear mandate is even divided among PHIs. One inspector who accepts calls about hoarding stated,

I don't think there is a clear cut mandate. I don't think anyone can point to a sheet of paper and say, "This is what public health does" and I don't. Because of that, it gives a

lot of freedom for how we are able to offer right now because there is no, at least I haven't seen it, I haven't seen a policy or procedure as this is what we do in these cases.<sup>3</sup>

This inspector further states that some PHIs believe that if an individual becomes entrenched in a hoarding situation, it is incumbent upon that individual to get himself or herself out of the mess created. While the PHI interviewed does not have this opinion but states that he has taken on the benevolent attitude taught to him by the PHI who acted as his mentor in these situations.

Another inspector clearly stated that the investigation of housing health hazards by the SDHU is certainly within their mandate, even if it is within a privately owned dwelling. He said,

These people live, you know, are neighbour to somebody, or in the community they are visible, and the way they live will, at some point, directly or indirectly, affect the neighbour, when there is smell, when there are bedbugs, cockroaches, lice, you know, they list sometimes, whatever, rodents, and so I mean there is this, definitely we do have jurisdiction to get in there.

A third inspector, when asked if they always responded with the same amount of involvement that they have now, he commented that he, personally, takes things much farther than inspectors did in the past.

Our inspectors just used to do a door knock and a guy would come to the door and would say "We had a complaint about your living conditions" and the person would say "Oh no, I am fine" and the inspector would walk away. I don't do that, I have to, like you know, I have to get myself into the place, take a look and make an assessment and so I probably come up with a solution for the person. I get them in contact with the proper agency or give them some ideas, "If you do this, this, and this, these other agencies are going to stay

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<sup>3</sup> Although the PHI stated that he or she had not seen policy and procedures, these documents do exist and are readily available to all PHIs.

off your back, like too much clutter, this and that, and the fire department could get involved”, especially in a multi-unit place and I tell them “You got to keep things away from your heating things, you got to make clear pathways, into the place, around your kitchen, and bathroom. You do that and at least it’s a start.”

Some agencies are not in a position to investigate and remedy housing health hazards but they provide a supporting role to the PHIs when called in. One inspector discusses how difficult it is at times to respond to individuals living in compromised housing situations who have severe health issues and are resistant to treatment. In a few cases, the paramedics and police were called in by the PHIs. The police are asked to remain on standby in the event that an individual resists being transported to the hospital by the paramedics. One PHI is of the opinion that it is always best to talk with individuals and convince them that what he is suggesting is in their best interest. However, this PHI informs some people that he is willing to get a warrant if they do not cooperate. Once the client has been transported to the hospital, this inspector would often go to the emergency department with pictures of the inside of their homes to give the physicians an idea of just how incapable these individuals are of caring for themselves. This type of intervention generally resulted in long term care placements for the clients, although not always. Police are also used when there is an issue of safety for PHIs and other workers. When David’s yard was being cleaned up in the fall of 2015, the police were present to keep the peace and to prevent David from interfering with the cleanup. It is incumbent upon police and paramedics to respond in these types of situations to fulfill their mandates.

Other agencies are less willing to respond to hoarding situations. Home care agencies do not send their workers into hazardous situations and withdraws services when it feels there is a hazard. These could be nursing services or homemaker services. A local mental health agency is

not always willing to be of assistance. It does not take referrals from other service providers as this type of referral is reportedly not within the agency's mandate. It is the agency's view that it is incumbent upon clients to seek services for themselves. This is problematic for people who exhibit hoarding behaviour as they often do not perceive their situation as one requiring a solution. David was of the belief that he could clean up his house by himself when this was clearly not possible. Occasionally, the hospital's mental health and addictions workers would be involved with clients who hoard in attempts to assist them with staying on top of the clutter, but this assistance appeared not to be consistent and the hoarding continued to be a problem. The SDHU received referrals from the hospital when a patient suspected of living in unsanitary housing situations was admitted. Patients were often held in the hospital for an extra day or two to allow the PHIs time to inspect the homes of these patients. The hospital, though, cannot remedy the housing situation and it cannot hold patients for long because it is not within their mandate to house individuals who otherwise would be inadequately housed. A formal group was created in the City of Greater Sudbury to handle the complex cases of patients having acute needs that do not require ongoing hospitalization. PHIs have participated in the past within this group but, according to one PHI, the group has evolved from its initial beginnings and is now not interested in chronic problems such as hoarding even though they come with acute manifestations. According to another health unit employee, the hoarding cases presented by PHIs to this group likely do not meet its mandate in that there is not imminent danger to individual who is exhibiting hoarding behaviour.

One PHI spoke about a time, eight years ago, when agencies would not talk to one another. An agency might call the health unit to report the location of a problem but would not provide a name. Often the address was an apartment building. The PHIs were becoming

frustrated because they could not respond after being notified of an issue. The health unit called a meeting of all involved parties, paramedics, police, building code inspectors, mental health personnel, and others to discuss the privacy issue that was standing in the way of the referrals. It was decided that these organizations would form a circle of care that shared only pertinent information such as name, address, next of kin so that they could “get the job done”.

It is clear that this kind of work requires a great deal of time and effort for the agencies that become involved. One PHI spoke about losing his whole summer to one hoarding case, and dealing with housing health hazards is a small part of the job. PHIs are also responsible for inspecting restaurants, checking septic systems, and checking water quality among other things. This PHI still indicated that responding to this call was within his mandate and the case required his attention.

One PHI made it very clear in a presentation he created to share information with other agencies that he considers it within the mandate of all service providers to attempt to help marginalized populations. In answer to his question “Did we have to get involved in these matters?” he responds,

- There are people out there who need to be helped but are not willing or able to ask for it
- There are people who will resist being helped even though they are in situations that are hazardous to their health
- We as front-line health workers should not make excuses why we can’t assist these marginalized persons. We should attempt to find a solution. (SDHU, 2012)

***Lack of options.***

Even though the PHIs contacted many different agencies, it was clear that they were frustrated with the lack of low or no cost options for resolving hoarding cases. At times, the PHI attempted to secure extra funding from ODSP but these funds were limited. A local home care agency offers homemaking services but it will not send staff into hoarding situations. There is a local, private company that works with clients exhibiting hoarding behaviour, both in cleaning their homes and providing psychological support, but this is a fee for service organization that many of the vulnerable clients seen by the SDHU cannot afford. This small cleaning company does not have the capacity to clean a home as cluttered as David's. These homes require industrial level cleaning at a high cost. Unfortunately, the industrial cleaning companies do not provide emotional support to clients during cleanout and, without this support, clients often persist with their hoarding behaviour. Ultimately, their homes revert to pre-cleanout status. Most of the individuals included in this study lived alone and many did not have the support of friends or family. They were older adults who often had physical limitations that precluded their taking on the level of cleaning required to remedy their hoarding situations.

Many of the individuals documented in the PHI records had issues with their mental health making it difficult to cope with the magnitude of the problem. A social service agency worker spoke about a cleaning service available in another municipality that provides vulnerable individuals, at little or no cost, with cleanup for hoarding situations and lamented about the lack of such a service in Sudbury. This worker thinks that Sudbury is far behind other municipalities when it comes to dealing with hoarding. One of the PHIs expressed her frustration about trying to access services for her clients. She says that resources are limited and that it is difficult to locate the right service for the right client:

There are so many criteria that people or vulnerable populations had to meet to get connected to those resources; that's almost a giant gap that we don't provide services for. You know you have got these clients, you have got these characteristics but this agency wants this, and this agency wants this, and poor vulnerable person doesn't fit anybody's mandate...

Even when homes were cleaned, there is no agency that follows up on these individuals to make sure that they do not continue with their hoarding practices. If a home is cluttered but presents no health hazards, or once a home with health hazards is cleaned up, it is no longer within the mandate of the SDHU. In rental situations PHIs often suggest to property managers that they use their rights of inspection to keep an eye on the hoarding situation and these PHIs volunteer to return if the property manager sees the situation getting out of control again. It is far easier to prevent the accumulation than it is to rid the home of hoarded items. Some of the repeat cases within the documented reports may have been able to avoid this repeat referral if the individuals had assistance on a regular basis with either basic cleaning or, at least, monitoring of the situation.

One of the documented cases clearly demonstrated what can happen between cleanups if no support is offered. An older gentleman had been referred to the SDHU in 2011, when his rental unit was in such poor condition that the fire inspector was involved. The unit was cleaned up then, likely by family, but in 2013 it was again in very poor condition. It was described as having waist high accumulation with no organization. The living room was not usable except for a small spot at the end of the couch to sit and sleep. The stove was not useable due to clutter and the bathroom was barely accessible. This client was ultimately moved out of his unit, possibly to a long term care bed. With some support after the cleanup two years prior, he may have been

able to stay in his own home, likely at a much reduced cost compared to that of a long term care placement.

### **Proposed solutions.**

There is one solution that everyone involved with individuals exhibiting hoarding behaviour agrees upon: formal coordination of services is required. Currently, a few of the agencies in the Sudbury area work together in an ad hoc fashion but there is no formal agreement between them. Some service providers met previously, but only to develop an informal agreement about the transfer of basic identifying data within a circle of care: name, address, and phone number of clients. There is currently no lead organization, although the SDHU takes this position at times. It is unknown how much other agencies deal with hoarding but, given that the SDHU has not run into these agencies in their experience with hoarding, it is unlikely that there are many services offered within other agencies. During the most recent meeting of service providers, when attempting to find a remedy for David, no solution was proposed. No one wanted to take charge of the situation. Even though the PHIs refer to fire services when they have concern for the safety of a client, the inspectors noted the difficulty in getting the fire services to do something when hoarding is severe and dangerous. One PHI says,

No, he wanted to, the [service provider] wanted to, but apparently his boss there didn't want to. He said, "What are we going to do? We are going to padlock the place and he is going to be on the street." So that's what they figured. He is safer, he is better off than living on the street. But is he? I don't see street people as dirty or as filthy as him.

One agency speaks of being very supportive of the SDHU taking the lead; it is certainly outside the mandate of this service organization to provide solutions for hoarding situations but it has a vested interest in maintaining the safety of its workers. One mental health agency is

educating their workforce about hoarding and one member of the organization thought that it would be most appropriate if they took the lead. Another thought that the role should remain with the SDHU because it has the ability to accept referrals and inspect the homes of individuals suspected of hoarding. Another thought was that municipalities should take the lead or, at least, co-lead with the SHDU. The reasoning presented is that the municipalities can be involved in such cases through by-laws and building controls. (However, by-law enforcement only becomes involved when hoarding effects extend beyond the walls of the home of single family dwellings.) The PHIs agree that someone needs to take the lead and it doesn't necessarily have to be the SDHU. "We need someone like a controller or somebody...who says who's needed to get the job done. It doesn't have to be us, it could be mental health, whoever is able or willing to take the job." Regardless of who takes the lead, it was suggested that there be protocols in place to remedy these situations, with all involved agencies working cooperatively for the betterment of the client.

One inspector spoke about changing the way PHI's are assigned to cases. With the recent retirement of one PHI who handled most of the housing hazard calls with vulnerable individuals, it has now fallen back to each PHI to respond to the calls within their given territory. The interviewed PHI thought that there were inspectors on the team who did not like responding to these calls and, therefore, would not fully follow through. He proposed a system and volunteered to be part of the system:

To make sure we put the best products forward to the public or to the marginalized individuals, umm, I find the only way you are going to be able to do that with the least amount of headache is going to be to have a specialized task force, specialized group of

inspectors who, among their other duties, they would be the ones to handle marginalized population calls.

The inspectors interviewed for this study all thought that the addition of a social worker to their team would be most helpful. One remarked, “Yeah, so I guess probably a social worker probably may be better suited than let’s say a health inspector because we are trained for, like, you know, infection control, this and that, restaurant inspection” and another said,

Knowing who to contact is invaluable. So even if there was one individual who know the system very well, maybe, umm, with a social work background... “Who do I contact?” and they said, “Oh, you just contact this person, this one, this one.” Very easy, I make five phone calls and I am done.

It was also suggested that training needs to be increased for anyone working with individuals who hoard and many people mentioned the need to bring in a physician from Toronto who specializes in treating individuals who hoard to offer a high-quality workshop to all personnel who work with hoarding cases. Public health inspectors currently receive little to no training in working with clients who hoard or who have comorbid mental health issues and they see the benefit of additional training. One PHI said,

In regards to dealing with the clients, umm, we don't have the psychological training, social work training, nothing like that to deal with it. Umm some people they never have been exposed to it before, they might not know the social cues or how to interact with them. Umm, people respond differently to different situation. So someone might be very aggressive, some people might not be comfortable speaking to someone who is breaking down and crying right in front of them. It's different, people react differently, and I find

that it's a little tricky trying to react as a social worker or psychologist without any of that training or knowledge or background.

One service provider thought it especially important to educate the public. If hoarding was better understood, he suggested, the community might be more willing to support individuals who exhibit hoarding behaviour. He thought that this may result in earlier referrals, which then might make the situations easier to resolve.

## **Discussion**

### **Client Characteristics**

The client characteristics found in this study are comparable to those found in much of the hoarding literature. The age of individuals who hoard in this study is similar to that found in a study by Samuels et al. (2008) but where they found twice as many male hoarders as female, this study found equal numbers. David had never been married, which was commonly reported in the literature (Steketee et al., 2001). In fact, half of the documented sample in this study, lived alone, which is again a commonly reported finding (Steketee, Frost, & Kim, 2001). The level of infirmity is also similar to that found in the literature although the reported level of mental illness locally is lower (Tolin, Frost, Steketee, Gray, & Fitch, 2008). This may have been a result of the question not being posed by the PHIs in this study. The lack of reporting in the rural areas of the SDHU catchment area cannot be compared to any reported studies as no studies were found in the peer reviewed literature that involved rural, remote areas.

There are many interesting comparison points between the literature on hoarding and David's life trajectory. Samuels et al. (2008) found that the odds of hoarding were four times greater in individuals who received excessive physical discipline when they were children. This certainly compares to Sally's description of David's life at home with his father. David's sister

also reported that David's hoarding behaviour took a turn for the worse soon after their father died. O'Connor (2014), writing from a psychoanalytical perspective, suggests that hoarding often emerges in cases of unresolved, unprocessed loss, such as the death of a parent. It is likely that David was in this position, especially given the description of his early adult life by his sister. David was a scavenger who rooted around in other people's trash. Of this behaviour, O'Connor suggests, "The hoarder takes home what others have thrown away. He can breathe life back into the dying. The hoard in turn can sustain his life..." (p. 107).

David's denial of his situation is common to hoarding cases. In a study of family informants, it was found that the majority of family members rated their hoarding members as having poor insight or as being delusional (arguing that there is no problem despite evidence to the contrary, as was certainly the case with David) (Tolin et al., 2010).

One of the unintended results of this study was the investigation of self-neglecting behaviour in addition to hoarding. David exhibited not only hoarding behaviour, but he also lived in squalor and neglected to care for his personal hygiene. In fact, up to 72% of individuals considered to be self-neglecters also exhibit hoarding behaviour (Poythress, Burnett, Naik, Pickens, & Dyer, 2006); thus, it is not unexpected that these two conditions were observed in David. This self-neglecting condition has been referred to in the literature by many different terms: self-neglect (Pavlou & Lachs, 2008), Diogenes Syndrome, senile breakdown syndrome, social breakdown syndrome (Doron et al., 2013), senile squalor (Middlesex-London Health Unit, 2000), and domestic squalor (Day, 2010). From a social constructionist perspective, "self neglect reflects the society's value of domestic and personal cleanliness and hygiene" (Doron et al., 2013, p. 19) and therefore represents more of a problem for others than it does for the one

considered to be self-neglecting. According to Pavlou & Lachs (2008) someone who self-neglects exhibits one or more of the following:

1. Persistent inattention to personal hygiene and/or environment
2. Repeated refusal of some/all indicated services which can reasonably be expected to improve quality of life
3. Self-endangerment through manifestations of unsafe behaviours (e.g., persistent refusal to care for a wound, creating fire hazards in the home). (p. 1842)

Physicians Pavlou and Lachs (2008) locate self-neglect squarely within the medical model when they argue that even though “proponents of libertarianism and unimpeded autonomy would likely recoil at the notion of a ‘disease-based’ approach to self-neglect, medical and psychiatric conditions probably underlie most cases” (p. 1845). Lauder (1999) discusses his “libertarian” view on the medicalization of self neglect when he says, “[h]ierarchical observation is the process of sustaining power by institutionalizing a particular branch of knowledge. This is, in part, achieved through professional journals which play a key role in legitimizing a particular construction as the truth” (p. 59). Lauder, a nurse, believes in the premise that self-neglect is a social construction and represents society’s abhorrence with a lack of cleanliness. He rejects the position of physicians that the “diagnosis” and “treatment” of self-neglect remain solely within the purview of medicine, no matter how many times physicians say so. The thinking of Pavlou and Lachs supports my earlier premise that the medical community medicalizes conditions that have a strong social component. The contrasting opinions, as expressed in this hierarchical thinking, can present difficulties when multi-disciplinary teams are formed to address problems such as hoarding.

Dyer, Goodwin, Pickens-Pace, Burnett, and Kelly (2007), on the other hand, paint a much different, and perhaps more realistic, picture of self-neglect. They suggest that individuals in this group lose the “cognitive capacity for self protection” (Dyer et al., 2007, p. 1675) through conditions such as dementia, depression and other psychiatric illnesses, diabetes, cerebrovascular disease, and nutritional deficiencies which are all common within the aging population. A lack of social services as well as issues such as poverty, lack of family, and lack of transportation also impact on the condition of self-neglect (Dyer et al., 2007). Service refusal is frequently portrayed as an essential part of self-neglect syndrome but one study found that the attitudes of service agencies may be part of the reason individuals do not want to engage with services (Lauder et al., 2009). Self-neglecting individuals are suspicious of statutory services as these services are often viewed as agents of social control and surveillance. From an ethical standpoint a professional working with an individual considered self neglecting must walk the tight rope while maintaining a “balance between preserving the elder’s welfare and maintaining their self respect, between identifying their *genuine* [emphasis added] wishes and identifying the need to protect them” (Doron et al., 2013, p. 20). In cases of self-neglect, professionals tend to focus more on risk and capacity of the individual which influences their choice of interventions (McDermott, 2010).

In their description of self neglect, Poythress et al. (2006) describe circumstances such as David’s situation so well that one would think they were describing his home. They describe an individual who is socially isolated, in poor health, with an unkempt appearance, living in squalor among overwhelming piles of garbage, insect and rodent infestation, newspaper, food containers, human and animal excrement, and lacking working utilities. These individuals are “often

comfortable in their surroundings, refuse intervention, and believe nothing is wrong" (Poythress et al., 2006, p. 7). Indeed, David described his situation as "comfortable".

Although it is well known that individuals who hoard often lack insight into their hoarding behaviour (Steketee et al., 2001) they do report being significantly less satisfied with their living arrangements than individuals who do not hoard and they also report lower subjective and objective quality of life (Saxena et al., 2011). David reports feeling "like a king" in his home when his health is good but one wonders if that is really what he feels or if it is bravado put on for the service providers he wants to impress. When David was in hospital after his stroke, with friends, family, and service providers visiting, he seemed truly happy, even after the decision to apply for long term care placement. One wonders if he is now thinking about what he has missed out upon due to his hoarding behaviour over the years.

### **Built Environment**

Nearly 80% of the seniors exhibiting hoarding behaviour have substantial to severe difficulty moving around their homes and those that have never been married, like David, were significantly more likely to have these difficulties (Steketee et al., 2001). David's house was both unsafe due to the extreme buildup of accumulation in every room, and unsanitary due to the presence of urine, feces, mice droppings, and rotting food. Steketee et al. (2001) found that 25% of hoarding older adults interviewed had overpowering body odour likely as a result of the clutter that substantially or severely limited their ability to maintain their personal hygiene. Bathtubs, showers and bathroom sinks were found obstructed or non-functional. Hoarding behaviour and neglect of personal hygiene and squalor do not always go hand in hand and all exist along a continuum. Some individuals who self-neglect go to great lengths to maintain their personal hygiene. Lauder et al. (2005) report that they found one individual who even used a

local swimming pool to maintain his hygiene at levels considered acceptable by societal norms. In contrast, David was provided with the option to shower at the drop-in centre but rarely used this opportunity. His house was at an extreme level of squalor. Even though he had many cleaning products visible in his bathroom, there was no indication that he ever used them given the condition of the kitchen, toilet, floors, and walls. Only the shower was clean but that is because it was seldom, if ever, used after its installation four years prior.

David's home, along with many of the homes that were documented in the three years analyzed, were unsafe. Blocked exits were not uncommon. In one case, it took the resident 10 minutes to clear things away from the entrance to his apartment to allow access by the PHI. In case of fire, it would have been impossible both for the resident to exit and firefighters to enter. Similarly, if the resident collapsed and needed an ambulance, paramedics would have great difficulty entering the residence. Lucini et al. (2009) documented the extreme danger for individuals who hoard. In their Australian study, they found that only 0.25% of fires occurred in the homes of people who hoard, but their chances of dying if caught in a preventable house fire was 24%. To compare that to the entire population of Australia, the chance of dying if caught in a structural fire is 0.0006% (Queensland Fire and Rescue Authority, 1998). This may be, in part, because only 26% of hoarding households have working smoke alarms as compared to 66% in the homes of the non-hoarding population (Lucini et al., 2009). In addition, the risk for fire is increased. David admitted that his wiring was old, yet he used portable heaters for warmth that he had plugged into extension cords that traversed an area which included a great deal of flammable material such as shredded newspaper. This highlights the exorbitant increase in the risk of dying in a fire living in a house characterized as affected by hoarding. One wonders, given these statistics, why fire services are so hesitant to act in cases of extreme hoarding.

There is risk not only to the resident but also to the fire fighter. In September 2010 a fire started on the 24<sup>th</sup> floor of an apartment building in Toronto (NFPA Journal, 2012). The cause was a lit cigarette which fell onto the lower balcony of an individual who hoards. The balcony was packed with paper, as was the apartment, and the fire quickly spread from the balcony to the apartment. The occupant of the apartment was not home but the rest of the building had to be evacuated. The fire was so hot that the fire fighters had to use extraordinary measures to put it out including keeping themselves cool with fine sprays of water as they approached the apartment from the hallway. The contents of the apartment were pressing against the door so it took extra time to enter. They were able to extinguish the blaze by spraying water directly into the apartment. It took seven hours, and 300 fire fighters to extinguish the blaze that, fortunately, was contained to the one apartment and hallway. Three fire fighter and 14 residents were treated in hospitals, three with serious injuries. Due to the concern of structural damage, all residents had to leave their homes temporarily rendering them homeless. The fire personnel swept through the building once the fire was contained to ensure that all occupants had been evacuated and they found another 14 apartments where hoarding presented a fire hazard. In response to this situation the Toronto Fire Marshall's office issued a plea to landlords to inform fire departments if they have concerns that they have tenants living in units that may be a fire hazard (Schorow, 2012). In the Sudbury area, it is often the SDHU that either calls the fire department or encourages landlords to call when they suspect that a home or apartment is thought to be a fire hazard. This often leads to homes being cleaned up, at least temporarily, to satisfy the fire inspector, but as we saw in David's case, there is reluctance to remove an individual from the home when the case is severe and is not cleaned sufficiently to make it safe. This situation also highlights how a situation, which some think should remain a private concern and not be amendable to outside

intervention, quickly becomes a concern for hundreds, if not thousands, of people. It is clear that the well-being of every individual living in a multi-unit complex is placed in danger by the hoarding behaviour of one individual.

### **Agency Factors**

To understand the response of the SDHU to hoarding complaints one must consider the legislation governing this response. Public health units, under the jurisdiction of the provincial government, are the body tasked with the maintenance of community health. The legislation in Ontario under which the PHIs operate is the Health Protection and Promotion Act (2016). Health hazards, as defined in s.1(1) of the act, are “(a) a condition of a premises, (b) a substance, thing, plant or animal other than man, or (c) a solid, liquid, gas or combination of any of them, that is likely to have an adverse effect on the health of any person.” The HPPA (2016) further suggests under Duty to Inspect, section 10. (1) that:

[e]very medical officer of health shall inspect or cause the inspection of the health unit served by him or her for the purpose of preventing, eliminating and decreasing the effects of health hazards in the health unit. A public health inspector may make an order when he or she has reasonable grounds to believe that a health hazard exists and “that the requirements specified in the order are necessary in order to decrease the effect of or to eliminate the health hazard” R.S.O. 1990, c. H.7, s. 13(2). An order may include vacating the premises, doing work in or about the premises, removal of anything stated as a health hazard from the premises, cleaning or disinfecting of the premises, or requiring destruction of whatever is specified (R.S.O. 1990, c. H.7, s. 13 (4)).

Lefebvre et al. (2012), stated in their study of PHIs in northeastern Ontario that the PHIs considered the legislation with respect to housing health hazards to be vague and one

recommendation from this study was that the legislation be amended to clarify the roles of the PHI in these situations. In 2015, a RentSafe Public Health Unit Survey in Ontario (MacDermid, 2015) found that only 63% of health units respond to a potential hoarding call by visiting the home. It is clear that not all health units interpret and respond to the legislation in the same manner. Given the dangers to the health and well-being of individuals living in multi-unit dwellings, as previously presented, it is difficult to understand how some health units do not consider it within their mandate to investigate hoarding complaints.

In the SDHU study, most PHIs considered the investigation of housing health hazards to be well within their mandate, even within private homes, and discussed why it was a part of their mandate. First, they believed that housing health hazards fit within the parameters of the legislation and second, the PHIs explained how housing health hazards can expand beyond the walls of the home of an individual to have an effect on the larger community. It may be that the PHIs of the SDHU were more committed to responding to housing health hazards within vulnerable populations because of the atmosphere created by the strong feelings of the one PHI who covered most of these calls. This passionate PHI, in a slide presentation used to educate PHIs and other agency workers, says, “I would rather be criticized for being too involved than be a witness at an inquest and try to answer why I didn’t attempt to rectify the situation” (SDHU, 2013). Another PHI liked the fact that the legislation was wide open because he felt that he could apply it more broadly when not constrained by specifics.

The companion document to the HPPA (2016) is the Ontario Public Health Standards 2008 (2016) which states that services should be provided based upon need and recognizes that there are segments of the population with greater needs than others. For the purpose of

understanding the PHI's role in responding to health hazard it is important to grasp the full reporting of this concept in the Ontario Public Health Standards 2008. It states,

It is evident that population health outcomes are often influenced disproportionately by sub-populations who experience inequities in health status and comparatively less control over factors and conditions that promote, protect, or sustain their health. By tailoring programs and services to meet the needs of priority populations, boards of health contribute to the improvement of overall populations health outcomes. (p. 20)

From this report, it is clear that problems affecting individuals often have structural origins.

Social determinants of health such as income insecurity, food insecurity, poor housing, social exclusion, unemployment, difficulties in early life, and lack health care services, factors often outside of individual control, can have a profound effect on the health of an individual (Raphael, 2009). From the interviews with the PHIs and in speaking with other health unit personnel, it is clear that the SDHU takes seriously its commitment to bridging health inequities. This is well demonstrated in their response to housing health hazards in marginalized populations. Paveza, VandeWeerd, and Laumann (2008) discuss in their model of risks and vulnerabilities for individuals who self-neglect, those vulnerabilities that lie within an older adult who is considered to self-neglect and those risk factors that are external to the individual. Risk factors include demographics, living arrangements, social support, history of abuse, unmet need for care, transportation, and neighbourhood characteristics. It is incumbent upon society to mitigate against these risks as proposed in the Ontario Public Health Standards 2008.

### **Proposed Solutions**

The individuals interviewed for this study had some clear ideas for potential solutions to the problem of hoarding in the area served by the SDHU. Not surprisingly, these are solutions

that have been identified in other municipalities. One case study of four homes consumed by hoarding included photographs of rooms which looked quite similar to David's (Franks et al., 2004). As was the case in the present study, all of these cases came to the attention of the authorities because of a crisis: repeated 911 calls, the threat of bodily harm to a neighbour, a child protective services referral, and a case of fraud. In the analysis, the authors concluded that signs of hoarding are noticeable long before the point of crisis and that, in lesser cases, service providers should assume that the problem is likely to get worse and "hoarding should be viewed as a significant emotional, social, and health problem instead of eccentricity or lifestyle choice" (Franks et al., 2004, p. 106). They also suggested that there be increased training and improved communication between social services and public health so that assistance is more readily available. In all four cases reported by Franks et al. (2004) people were aware of the difficulties but they did not know where to turn for help. It appears that all services need to do a better job of informing the public, both of the dangers of hoarding and of the services that they provide.

McGuire et al. (2013) suggest that agencies often do not have a standardized protocol for remedying hoarding situations and the majority of their workers are not trained to handle hoarding cases, which may be part of the reason that they found a 52% recidivism rate in the group they studied. Unfortunately, in any unaddressed chronic condition, consequences usually escalate. In the case of hoarding, this escalation may result in a home being condemned, a tenant being evicted, or a poorer health outcome for someone living in these conditions. The situation, as described by McGuire et al., parallels that of the SDHU and area agencies, in that training is definitely lacking as is a standardized protocol for an approach to hoarding. What exists is the overarching HPPA which provides no guidance to PHIs when approaching a hoarding situation.

McGuire et al. (2013) found that most of the inspectors surveyed only saw two or three cases a year. This has not been the situation at the SDHU. One PHI delivered most of the services to the hoarding population in the last few years but this is unlikely to be the case in the future. This PHI has now retired and it is expected, going forward, that each PHI will investigate those hoarding cases that fall within their territories. Having limited numbers of cases makes it difficult to build relationships with other agencies and their employees and to keep up to date on the latest hoarding knowledge and protocols.

Complaints to health departments come from neighbours, fire personnel, police, social service agencies, and service personnel visiting the homes (Frost et al., 2000). Only half of the hoarders in a study by Frost et al. (2000) recognized the lack of sanitation in their homes even though the health officers listed 88% of the homes as unsanitary because hoarding interfered with basic hygiene and food preparation. These cases typically involved multiple agencies at significant cost to the communities. The health departments made an average number of three repeat visits to each home with a range of 0 to 12. Additional agencies were involved in 79% of cases and almost half of the cases studies by Frost et al. (2000) involved three or more agencies. Forty percent of the people with hoarding behaviour in their study refused to cooperate and had some or all of their possessions removed by the municipality. In nearly half of these cases, the building in which they lived was condemned or the tenants were evicted, with a third moving to assisted living facilities. Frustration was reported by the health officers as inconsistent judicial rulings complicated case resolution.

In the current case study, a multitude of agencies was involved including first responders, the hospital, a home care agency, a mental health organization, a mental health and addiction department, building inspectors, animal control, and drop-in centre to mention only a few. One

segment that was poorly utilized in Sudbury as compared to other studies was mental health services. The SDHU rarely referred to a local mental health organization as it was unwilling to take direct referrals from another agency. It is incumbent upon the individual to seek care for him or herself from this agency, according to its mandate. The mental health and addiction services associated with the local hospital saw a small number of these SDHU clients over the three years and another two were admitted to hospital for mental health services but these numbers do not approach those seen by Frost et al. (2000). It may be necessary for the SDHU to forge relationships with additional mental health service organizations within the community so there are mental health referral options open to the SDHU.

There was one interesting side note with respect to agency support with David's case that was also seen in the documented cases. Animal control takes its role in the protection of animals seriously. Animals were often removed from unsafe homes long before their owners were. This makes one wonder why the social safety net for people is not available in the same way that it is for their pets. Why did David's dog have a new home when he did not? Although David's home was not suitable for human habitation, he had nowhere else to go once discharged from hospital.

It has been suggested by many authors that multi-disciplinary task forces are the way for a municipality to provide optimal services to individuals who hoard (Frost, Steketee, & Williams, 2000; Bratiotis, 2013; Brown & Pain, 2014; Koenig, Spano, Leiste, Holmes, & MacMillan, 2014). This approach is necessary for both individuals who hoard and those that serve them. It has been noted by many that treating individuals who hoard is both time consuming and stressful since successes are few (Frost, Tolin, & Maltby, 2010; Muroff, Bratiotis, & Steketee, 2011; Steketee et al., 2010). Even for individuals in crisis due to impending eviction by a landlord or removal from their own home by the fire department it is

difficult for them to discard any of their possessions (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2014) This was the case for David and others within the documented records.

Once hoarding behaviours spill over into the community there is the added difficulty of knowing when and how to intervene. Referrals are often made to multiple agencies but hoarders are often not interested in their services (Chapin et al., 2010). This creates an ethical dilemma: how do we satisfy the needs of the community without encroaching upon the rights of the hoarder?

Although most hoarders deny that they have a problem, many of them live in squalor (Koenig, Spano, Leiste, Holmes, & MacMillan, 2014) as did David. Assistance is often not sought by individuals exhibiting hoarding behaviour as they have poor insight into their behaviour (Steketee et al., 2001; Tolin et al., 2010). This creates an ethical dilemma within society between self-determination and the protection of life (Day, 2010; Poythress et al., 2006) and, since most of these hoarding individuals are not in position to be declared incompetent, the acceptance or rejection of treatment is their choice. Practitioners most frequently honour the hoarder's right to self-determination even when hoarding presents significant danger to the health of the hoarder (Koenig, Leiste, Spano, & Chapin, 2013).

Because hoarding is progressive, the lack of early support and treatment may result in hoarding advancing to the point where the community becomes involved through bylaw enforcement, animal protection enforcement, or eviction and the hoarder has no other options but to comply or suffer the consequences of not complying. Non-compliance may result in seizure of animals, forced cleanup, or eviction. For some seniors, the result is non-consensual placement in a nursing facility (Frost et al., 2000; Chapin et al., 2010; Koenig et al., 2014). David experienced all of the previous consequences.

According to Koenig et al. (2014), hoarders are often in denial and resist professional help. As a result, in situations where their behaviour must be changed because of recognized bylaw infringement or possible eviction, they may be considered involuntary clients. Social work, because of its history of working with marginalized populations and history of working for the purpose of both social control and social change, may be the appropriate profession to spearhead any coordinated effort targeting hoarding behaviour (Koenig et al., 2014). An approach has been suggested which “regards professional practice with involuntary clients as a political process resting on the use of the professionals’ power due to the assumption that the nonvoluntary client and professional have conflicting interests” (Koenig et al., 2014, p. 85). In situations such as these it requires the social worker “to be up front with clients regarding the nature of their work and to acknowledge that they are acting on behalf of the larger society and not necessarily in the clients’ interests” (Koenig et al., 2014, p. 85). In situations where the social worker is able to establish trust with the client, a bargaining process may ensue. Coercion, the use of power to elicit compliance regardless of client wishes, is used where consent is never achieved. This may be necessary in the event of an eviction notice.

There is another side to this ethical dilemma which may be more difficult to solve. Hoarding is known to be more prevalent in lower socioeconomic classes. The odds of hoarding are over four times greater in the poorest as compared to the wealthiest households (Samuels, et al., 2008). Traumatic events, both in childhood and adulthood, have been associated with hoarding behaviour (Hartl, Duggany, Allen, Steketee, & Frost, 2005). Individuals who hoard are more likely to have experienced a greater frequency and greater variety in types of traumatic events, including having something taken by force, being physically disciplined or assaulted or being forced to partake in unwanted sexual activity (Hartl et al., 2005). This makes one wonder

about the failings of society to assist and protect these individuals early in their lives before their hoarding behaviours had the opportunity to develop. More than half of the hoarding population has other mental health issues that may not have been treated early on, possibly due to the unavailability of these services (Frost, 2011). Are there enough services available in a timely fashion for individuals requiring support? Is there any way, by providing early intervention for issues that underlie hoarding, that society could circumvent later problems? Have we, as a society, failed to protect these individuals?

Treatment for hoarding has been found to be long and expensive and recidivism is high (McGuire et al., 2013; Rodriguez et al., 2012; Steketee et al., 2010). Because of detrimental conclusions to many hoarding cases, some communities have created task forces to assist hoarders who become caught up in the enforcement of community standards. There have been more than 85 created within the last 15 years (Bratiotis, 2013) and, although these task forces have had their difficulties, they have had many successes (Whitfield, et al., 2012). A description of the development of these multi-disciplinary task forces and the teams they create will provide an example of what can be done within the community to ethically support people who hoard.

#### **Multi-disciplinary task forces to address hoarding.**

Community collaboration has been said to be the very thing that successfully reforms health systems because of its shared responsibility, team approach, and increased pool of resources (Whitfield, Daniels, Flesaker, & Simmons, 2012). It utilizes ecological theory which suggests that both the causes and solutions of health and social problems lie beyond the individual and can be associated with such social determinants as available health care and social services (Pavezza et al, 2008; Whitfield et al., 2012). When a group of agencies join together to support a vulnerable population such as elderly hoarders, it creates the potential for an approach that builds upon the strengths not only of the vulnerable, but of the service providers as well (Whitfield et al., 2012).

Hoarding strains community agencies' fiscal and personnel resources (Bratiotis, 2013). Task forces are often born of the frustration, stress, and fatigue of front line staff dealing with hoarding behaviour because agency costs are high, time investments are large, successful outcomes are few, and the length of engagement is prolonged (Bratiotis, 2013). It is hoped that collaboratively these groups can influence systems and policies within communities. Their missions are to better understand hoarding, develop coordinated response, improve intervention outcomes, educate members and the community, change policy, secure funding, advance research, and maintain a presence in the media (Bratiotis, 2013). Generally, these task forces operate with no dedicated, sustainable funding. They are bottom up, grassroots organizations whose members take on the role with no compensation. Members of enforcement agencies recognized that enforcement alone was not going to solve the hoarding problem. Clean-outs, which were the initial responses, were not effective. The inclusion of mental health support is a more appropriate response (Brown & Pain, 2014). On a multi-disciplinary team some disciplines such as social work and nursing take on the role of friendly helper while others serve as regulators (housing code enforcement, fire safety) (Bratiotis, 2013). Advocacy becomes important within a task force, for once collaboration is achieved and both regulatory and therapeutic personnel are working together for the benefit of the client, it becomes clear that it is impossible to properly manage a hoarding situation by writing citations for clean-outs with turnaround between seven and 30 days. Lengthening time allowances provide the treatment team the opportunity to build the relationships necessary for the implementation of harm reduction with their clients (Bratiotis, 2013).

An ecological perspective is necessary when viewing hoarding at the community level. One must consider the individual characteristics of persons who hoard, their home environment,

informal support systems, public sector services, societal norms, and the interactions between these (Chapin et al., 2010). Social workers with their “person in environment” focus are trained in using this type of approach. Cognitive behaviour therapy has been used to treat hoarding disorder but it time intensive, expensive, and there are few trained clinicians (Chapin et al., 2010; Steketee et al., 2010 ). Multi-agency hoarding teams can address biopsychosocial factors within the individual as well as their interactions with environmental and systemic factors such as lack of funding (Chapin et al., 2010; Whitfield et al., 2012). Some of the barriers to these teams are the lack of empirical data on best practices for intervening early, lack of common assessment tools across agencies, legal, and ethical issues (Chapin et al., 2010). Forced cleanout without consent has been shown to actually worsen symptoms and contribute to recidivism (Brown & Pain, 2014). Anecdotal reports from regulatory agencies suggest that working alongside social workers helped to refine referrals and incorporate a strengths-based approach with promising results (Chapin et al., 2010). Employees of a regulatory agency have the authority to enter a residence but a social worker without this mandate may have difficulty gaining access to perform an assessment and develop a plan of intervention. With coordinated approaches, people can be empowered by including them in the process. Social workers can assist regulatory bodies by gaining the trust of the person who hoards so that, slowly, changes can be made. Together, strategies such as negotiations with the courts for prolonged cleanup periods may be possible.

The difficulty with hoarding teams are many: their members have diverse backgrounds and orientations, they are from different professions with no common codes of conduct, they represent an uneven distribution of power, they share minimal or no common conceptual understanding of hoarding, and they have differing perspectives on the ethical dilemmas sometimes present in a hoarding case (Koenig, Chapin, & Spano, 2010). For example, an animal

control officer places the safety of animals ahead of the desires of the owner to have these animals. Koenig, Chapin and Spano (2010) suggest that, for a multi-agency task force to properly handle hoarding cases, they should ask themselves these questions: who?, what?, why?, how?, what are the foreseeable events?, and what are the viable alternatives? How a client system is defined will affect the chosen intervention? Is it the client, client and family, or client and community and how are the concerns of each balanced? What are the facts and whose version of the facts take precedence? What is motivating the decision makers, the task force members, the hoarders, and families? How should people who hoard, family members and others participate in referrals to other agencies and at what point in time? What are the consequences of intervening or not intervening on the person who hoards, family, and community? Are there any alternatives and according to the person who hoards, family, and team members, which are most feasible? Ethical decision making must balance the rights and responsibilities of multiple players. No one person's right to hoard can be understood without placing these rights in the context of the community. Relationship building is the vehicle for managing all sides of the potential conflict (Day, 2010; Koenig, Chapin, & Spano, 2010; Whitfield et al., 2012). The positive effects of relationship building can be seen in an innovative program created to address hoarding in Edmonton, Alberta

**“This Full House” initiative.**

Unfortunately, there is no comprehensive, provincial process to support older people living in the community who exhibit compulsive hoarding behaviour. Nor is there a federal strategy in Canada to support aging in place. There are a few innovative programs in Canada that have attempted to provide a solution within municipalities. One of these, named “This Full House”, was implemented with the aims of keeping people who hoard from being evicted, improving their health and well-being, and maintaining positive social contacts for the hoarders (Whitfield et al., 2012). One health inspector aptly described the

status quo prior to “This Full House”: “It was up to the health inspector to try and play all roles and just nag people into cleaning up. Which was mostly unsuccessful and wasn’t really our job. I mean we are not social workers, we’re not mental health workers, we are public health inspectors” (Whitfield et al., 2012, p. 6). Since the inception of the program, a social worker, public health worker, and other members as necessary collaborate with the hoarding client to bring about change.

The most important part of this initiative is to allow seniors to age at home. This is accomplished by having a professional organizer assist with cleaning the home. The social worker provides non-judgemental support to assist the person who hoards in dealing with issues of parting with belongings by helping him or her to understand that hoarding behaviour is not his or her fault. The approach is one of harm reduction with all efforts focused on safety. It is understood that the behavioural change will be incremental and that change will be maintained when the client has decision-making power to influence goals and put them into action. This plan involves home visits by social workers, public health nurses, and geriatric nurses which aids in combatting the loneliness these seniors often face. Support groups are provided that allow people who hoard to connect with others that have similar experiences. Not only have the people who hoard benefitted from this program but participating service providers have found that they have also benefitted from access to the expertise of other members of the team.

### **The use of social work teams to address hoarding behaviour.**

In the London Borough of Hammersmith and Fulham, England, Adult Community Social Work (ACSW) teams are the lead agency in hoarding cases (Brown & Pain, 2014). There is increased risk from hoarding in inner city situations due to high density populations. In the United Kingdom, hoarding has typically been viewed as a housing or environmental health issue, especially when people who hoard live in social housing or multi-occupancy buildings. When a property is overrun with vermin or is filthy, environmental health services have the legal

obligation to enforce the clearing of the home or to evict. Previously homes were cleared out without consent but the results were temporary as the people who hoard just proceeded to rebuild their stash. As a result, it was decided that the ACSW teams would take the lead and all agencies would refer to them. The Clutter Index Scale is used to prioritize the timing of interventions. Moderately cluttered homes require visits from the ACSW in combination with members of the London Fire Brigade, environmental health, or housing officers and all jointly assess risk and complete hoarding assessment forms. Case conferences including all involved agencies and the person who hoards, if possible, are called to formulate a plan to address the hoarding situation. Severe hoarding presents a serious fire and health risk to the individual and others. In this case, an urgent multi-agency case conference is called to develop an action plan. The social worker will immediately work with the person who hoards in order to minimize risk. This plan will require long term commitment from the social worker and it is best if one specific social worker attends the person who hoards so that a strong relationship may be forged. It is necessary for the social worker to meet with the person who hoards at least every two weeks for at least two hours at a time. Since ACSW has become involved there have been no evictions due to hoarding. The London Hoarding Task Force is also used to establish local authority protocols, maintain a database of persons who hoard and the costs involved, share information, provide training and support, review case studies, provide clarity on legislation, and run a monthly hoarding support group (Brown & Pain, 2014).

**Recommendations for hoarding task forces for the SDHU catchment area.**

Since there is no coordinated intervention for hoarding in the SDHU catchment area, it would be prudent, based upon the success of initiatives in London, England and Edmonton, Alberta, to create multi-disciplinary task forces within the City of Greater Sudbury to consider

the future direction of interventions to remediate hoarding behaviour. Within these task forces, agencies currently involved with clients who hoard and agencies that may be in a position to offer support would come together to create an action plan. This would be most successful if one agency takes the lead. Unfortunately, with the current climate of underfunding in mental health treatment, this may be a challenge. Ultimately, a coordinated effort may save both financial resources and personnel by eliminating duplication of services. Based upon recommendations of Chapin et al. (2010) and Brown and Pain (2014), social work should be an important component of any team assembled to combat hoarding. Initially, the education of the hoarding team will be an absolute must so that all members understand what is required for a successful outcome. Consideration should be given to pairing regulatory agents with social workers to allow social workers the means to access the homes of persons who hoard who may otherwise not grant access. Harm reduction should be the treatment of choice due to the time and resources required to combat hoarding behaviour. Brown and Pain (2014) report that it sometimes takes months for a social worker to develop a trusting relationship with his or her client. Self-help groups should be initiated as they have been proven to be very helpful to persons who hoard who lack both insight and socialization (Bratiotis et al., 2013; Brown & Pain, 2014; Simmons, 2009). Information about other resources, such as internet support groups, should be collected and offered to hoarding clients as they, too, have proven beneficial (Bratiotis et al., 2013). Since isolation, loss, and disconnection are so common among individuals who hoard and self-neglect, a multi-agency, multidisciplinary, coordinated approach would go a long way toward improving social networks to reduce this disconnection (Day, Leahy-Warren, & McCarthy, 2013).

It also may be necessary for the multi-disciplinary task force to insist upon regulatory changes. Persons who hoard are unable to clean their homes within the short time periods given

by regulatory bodies. Government lobbying will most certainly be necessary to secure adequate funding. Persons who hoard are often a vulnerable population at risk of eviction and possible homelessness. It is incumbent upon service providers to advocate on their behalf. Advocating for an increase in mental health services across the board would be beneficial so that services are available to young people caught up in traumatic events so that they may resolve their conflicts, thereby lessening their chance of becoming persons who hoard in the future. Due to the many concurrent mental health disorders found in conjunction with hoarding, an increase in mental health services is required so that all individuals requiring mental health services can avail themselves of these, regardless of their ability to pay.

### **Coalitions existing in Canada.**

Three well documented coalitions to assist individuals who hoard and self-neglect have been established within Canada in the last fifteen years. They include the *Middlesex-London Health Unit Task Force on Senile Squalor* in London, Ontario (Middlesex-London Health Unit, 2000), *This Full House* in Edmonton, Alberta (Whitfield et al., 2012), and *No Room to Spare* (Dinning, 2006) in Ottawa, Ontario. Although Edmonton and Ottawa are cities with about five times the population of Sudbury, London is only twice its size and it was able to develop its program almost 15 years ago for seniors who self-neglect. Both Ottawa's program (Dinning, 2006) and London's program (Middlesex-London Health Unit, 2000) are operated by the local health unit but Edmonton's program was implemented and maintained by social workers from the Seniors Association of Greater Edmonton (SAGE) (Whitfield et al., 2012). Since the problems in these three cities vary little from the situation in the Sudbury area, it seems futile to reinvent the wheel. Although not all components of these programs may be suitable for the Sudbury area; it stands to reason that this coalition begin with a discussion of local problems and

then move on to consider how they might possibly adapt components of the other three successful programs.

The Middlesex London Health Unit Task Force on Senile Squalor was initiated because it was evident that individuals exhibiting self-neglecting behaviours were falling through the cracks between agencies and legislation (Middlesex-London Health Unit, 2000). The strict confidentiality laws present in Ontario were preventing agencies from sharing information for the effective coordination of services. This task force also hoped to find a method for early identification and timely intervention because they thought cases were being identified too late when the self-neglecting behaviour was firmly entrenched. The health unit already had a Special Risk Recluse Program which is an at-risk registry that they suggested be expanded to include the possible influx of cases. The individuals on this list are monitored at least twice a year by PHIs and public health nurses. The list includes individuals who have a grave chronic illness, are physically incapacitated, living in unsanitary conditions, and/or self-neglecting who are not receiving care from any other organization and who will not accept active care. Shared leadership and partnership were considered crucial to ensure that momentum would not be lost between task force formation and implementation of the program. The Middlesex London Health Unit took the lead. It was suggested that the Gatekeeper program, a program where community members who come into contact with at risk elderly, such as mail carriers, meter readers, bank tellers, and property managers could be recruited and trained to recognize the risk factors for older adults; such individuals could be recruited in hopes of increasing early identification of older adults at risk. The task force recommended that initial visits be conducted by a registered nurse or social worker and that a psycho-geriatrician make a home visit within two weeks. It was understood that the individual did not have to consent to assessment and that, unless there was

diminished capacity, assessment could not proceed. A web search of services offered by the Middlesex-London Health Unit (2016) indicates that this Special Risk and Hoarding Program is currently offered in conjunction with the London Fire Department, Canadian Mental Health Association (CMHA), Community Care Access Centre (CCAC), and other community mental health partners.

Ottawa's program, *No Room to Spare* (Dinning, 2006) has created their response to hoarding to be similar to the four pillar response to drug addiction which includes prevention, treatment, harm reduction, and enforcement. A multi-disciplinary response using a very specific response tree was created based upon the response in other communities in the United States. An important component of their program is a system navigator who would direct an individual who hoards in the right direction at the right time. In their response to hoarding, Ottawa Public Health has included a treatment regimen (Dinning, 2006).

### **Implications for Practice**

From the outset, the purpose of this study was to uncover barriers in the remediation of housing health hazards—specifically hoarding—occurring within the area served by the SDHU, based on interviews with PHIs and other service providers, an individual exhibiting hoarding behaviour and his family. Multiple barriers were discovered within characteristics inherent to the hoarding individual, his or her environment, or the agencies that respond or don't respond to hoarding. Although the numbers of hoarding cases in the area served by the SDHU do not appear to be great, the ones studied represent referrals to the SDHU only. There are likely many more cases that go unreported and, if the Sudbury area was to implement a program, there would likely be many more referrals. In Edmonton, “This Full House” experienced a doubling of referrals in their second year and an eight-fold increase in year three (Lilwall, 2010). Considering both the

results of this study and a search within peer reviewed and gray literature, recommendations have been devised for both the SDHU and its represented municipalities. It is hoped that both the SDHU and governing bodies will consider these recommendations. From a health equity standpoint, it is incumbent upon all bodies to focus their efforts on this marginalized population.

### **Recommendations for the Sudbury & District Health Unit**

1. A meeting of the Environmental Health Division should be called to discuss the content of this report.
2. The Environmental Health Division should connect with the PHIs working outside the City of Greater Sudbury to ensure that they consider responding to potential housing health hazards to be a part of their activities. If a difference in approach is not found, then there needs to be further investigation into the lack of referrals in outlying areas.
3. The Environmental Health Division should consider the appointment of one or more PHIs to a specialized team that will be responsible for responding to potential housing health hazard calls including hoarding.
4. The Sudbury & District Health Unit should consider hiring a social worker as a systems navigator to assist the public health inspectors in the resolution of hoarding cases.
5. A written protocol should be designed by the Environmental Health Division that will standardize the way that hoarding complaints are handled by the division.
6. The Environmental Health Division should consider revision to the way hoarding cases are recorded. It is suggested that a form be created that includes check boxes so that critical information can be recorded in a standardized fashion. This will be especially helpful for repeat cases.

7. The Environmental Health Division should consider the adoption of the Clutter Index Rating (Steketee & Frost, 2007) to measure the severity of hoarding.
8. The Sudbury & District Health Unit should survey social service agencies within Sudbury to ascertain their current level of service for individuals who exhibit hoarding behaviour and to ascertain their willingness to serve these clients in the future. Social service agencies should also be questioned about their willingness to participate in a coalition that will examine the coordination of services in Sudbury for individuals who hoard.
9. The Sudbury & District Health Unit should approach councils of the municipalities contained within their catchment area to gain their support for a coalition to address hoarding in the area.

### **Recommendations for the municipalities served by the SDHU**

1. The SDHU should call together representatives of service agencies within their catchment area including, but not limited to, hospitals, police, fire, paramedics, home care agencies, drop-in centres, and mental health services as well as representatives of the municipalities served by the SDHU to discuss the formation of a coalition to coordinate services for individuals exhibiting hoarding behaviour.
2. This group should discuss what is required within the SDHU catchment area to address the problem of hoarding and should create a structure for the group going forward including who will lead the group.
3. Based upon coalitions in other Canadian cities, it is suggested that the local coalition consider the following:

- The designation of key employees within involved agencies to better provide a consistent, coordinated response;
- A central case management service that will review referrals, facilitate assessments, and assign cases to the most appropriate bodies;
- Inclusion of social workers;
- Community gatekeepers for early referral;
- Special Risk Recluse Program;
- Education strategies for service providers;
- Education strategies for the public to encourage early identification;
- A peer support group for individuals who hoard;
- Treatment options;
- The creation of common guidelines and protocols for all involved agencies;
- The creation of a referral list of all service providers and a detailed list of services that they offer;
- Integrated service delivery;
- Advocacy for increased funding for services to address hoarding;
- Regular collection of data to better understand the scope of the problem in the SDHU catchment area;
- Program evaluation for process, outcome, and impact.

### **Limitations of this study**

This thesis project is part of a larger study intended to inform the SDHU of barriers and facilitators to remedying housing health hazards for those within marginalized populations who are referred to the SDHU for inspection of their homes for potential health hazards. In analyzing

historically documented housing health hazards, it was difficult to isolate hoarding cases as hoarding was not scored by the PHIs. As the presence of hoarding was only interpreted by reading records after the fact, the recording of differing amounts of clutter and the extent of adequate pathways may have been misconstrued. This may have resulted in including some individuals whose homes are only cluttered who do not hoard and it may have missed others whose clutter was underreported. The participant upon which much of this case study was based, exhibited extreme hoarding behaviour. The study findings are not meant to be generalizable to a larger population. However, it is expected that data gathered and presented will be of benefit to a larger audience especially given the similarities of this study to other jurisdictions. The attempt in this study to compile and describe the characteristics of the hoarding cases in the previous three years, may have generated some errors and thus the findings of the review of cases should be viewed with caution. The records of the PHIs are in paragraph form; it is up to the individual PHI what he or she records. There may have been records where data was not entered because it was considered unimportant to the case at hand or because it was forgotten.

Another limitation to the study is that there were no cases reported outside the City of Greater Sudbury even though the population division between the city and outlying areas in the SDHU catchment area would suggest that, statistically, one would expect 20% of the cases to occur outside the city limits. It is doubtful that cases do not exist outside Sudbury. Recommendations presented herein, therefore, may be less applicable to outlying areas. This is certainly a limitation because one of the original goals of the research was to explore the issue in the rural communities within the SDHU's jurisdiction.

A significant limitation in this case study was the inability to re-interview David, the central client in this study. Because David suffered a stroke before he could be re-interviewed

after deficiencies were discovered in the transcript of the first interview, there were some gaps in his story. Attempts were made to fill in these gaps by interviewing his sister and the PHI involved in his case four years prior; these strategies provided the missing facts, however, they did not provide David's perspective on the missing information.

### **Reflexivity**

One of the process goals in constructing this thesis was to include reflexivity. I considered it important to conduct the study while remaining within a social constructionist framework. It was also necessary for me to continually bracket my views so that I did not impose them on the data collection processes, analysis and interpretation and I maintained a record of this information. This process was revealing. When I first began my literature search for this project, I was still unsure if this topic would indeed be the basis of my thesis. I was interested in the recent inclusion of hoarding in the DSM-5 and its connections with other mental illnesses. I began focusing on definitions of hoarding and treatment for hoarding—all medical constructs. It then occurred to me that I was falling into a perspective embedded within the medicalization of a problem that occurs on a continuum, which would certainly be defined differently by the individual diagnosed as a hoarding client and the one doing the diagnosing. It was then that I completed a literature search on the topic of medicalization and one of its alternatives, social constructionism, and committed myself to abandoning the positivist, medical model. Although I do not completely reject the DSM-5—that would be foolish given its reverence in some circles—I accept it only for the meaning that it provides to the individuals who insist upon using it. At first, I thought I would have great difficulty doing so, but it proved not to be as difficult as I first thought. Although, in the early writing of my research proposal I used the term “hoarder” to represent someone living in serious clutter, I no longer even think of these collectors as

“hoarders”. “To hoard” according to the Oxford Dictionary (2016) is “to accumulate (money or valued objects) and hide or store away”. Initially I did not think that definition accurately fit the situation observed in this study wherein individuals collect items, material goods and garbage, thrown haphazardly about, but not hide it at all. Upon reflection, I decided that my initial response was wrong. Value is subjective. What I value and what someone else values are different things. The hoarded items viewed in this study were, indeed, valued by the individual who collected them. I then took exception to the idea from the definition indicating that the objects must be hidden, but upon further reflection and immersion in the study, I gained deeper understanding. The individuals who amassed an extraordinary number of belongings in this study did hide them away. These individuals hid them in plain sight, but the extremes were only evident if you entered their homes. People who engage in hoarding usually lived alone and did not invite others to visit; they were hiding along with their belongings. What this means is that I do not reject the word “hoard”. I only reject the noun, “hoarder”. I consider this to be an important difference, as individuals who hoard generally do not consider themselves hoarders. Using the terminology “people who engage in hoarding behaviour” instead of “hoarder” maintains the humanity of these individuals rather than objectifying them. Psychiatrists and even the general public may consider them as hoarders, but I reject this construction because the individuals who hoard generally reject the construction. Other associated words, such as collector or gatherer, may be less negative in connotation.

What I found more difficult was to keep myself bracketed. This occurred more when speaking with the PHI's. They knew that I was a social worker and discussed their role as that of a social worker when I went out in the field with them. When I created a semi-structured interview guide I asked the PHIs whom I interviewed whether they considered themselves to be

doing the work of a social worker, to which they replied “yes”. This was a biased way to ask the question. At the time, I thought that I was asking them the question in this manner because the PHIs were presenting the information in this manner to me in the field, but I now reject this idea. I am a new, eager social worker. From my literature review, it was clear that social workers were considered an important part of a team working with individuals who hoard, which I knew when meeting with the PHIs. This episode was an excellent example of how meaning is made between two people. I think, in actual fact, the meaning ascribed to their position by the PHIs was constructed between us. I do not know if there would be any way to bracket myself other than to have been less forthright about my education but I recognize that I erred in asking the question the way that I did.

Band-Winterstein, Doron, & Naim (2014) suggest that, although most of the time when a researcher is trying to bracket him or herself it is based upon gender, ethnicity, or age; yet in this type of research it is important to bracket based upon the differing perceptions between participant and researcher of the way life should be lived. This latter approach respects the lived experience of the participant. It was interesting to discover, through the process of reflection, the feelings aroused within me when studying this topic. I found it strange that I had two people close to me when I was in my teen years who had large amounts of clutter in their homes, but I had not thought negatively about those individuals. Nor, did the individuals in this study raise any negative feelings within me. It was more a response of intrigue. Although I do not collect like the individuals in this study, I have been called a “hoarder” by my children. I have thousands of books in my home, most of which are neatly arranged in bookshelves, but many would consider this excessive. I can relate to my participant, David, in a way. We just collect differently and my approach is socially acceptable.

The feelings aroused within me by my participant and his situation were many. As the initial interview with David was conducted by one of my co-researchers, I did not meet him until two weeks after his stroke when he was still in the hospital. My first thought was that he looked just like my husband with his long, gray hair and long, gray beard. The second thing I noticed about David was that he had beautiful skin. This was in stark contrast to my vision an hour later when I visited his house. It was far from beautiful. Upon entering his house, my reaction was, “How could anyone live like that? Why would anyone live like that? Why would they want to continue to live like that?” I felt pity for David and intense sadness at his situation. I was glad that I was not in a therapeutic relationship with David because I did not feel empathy. I was sympathetic but not empathetic. Immediately, I wanted what I thought was best for David and that was his placement in a new home, preferably a long term care facility. I did not think about what David wanted, I thought about what I wanted for him. It was not until I heard about David’s story, as told by his sister, that I began to feel empathic. David’s earlier life might have precipitated his hoarding tendencies. He had no control over his behaviour and it was not his fault. Reflexivity was an immensely important learning piece in the creation of this thesis. It is a lesson I will not soon forget. It *will* make me a better social worker.

### **Conclusion**

This case study included one individual exhibiting hoarding behaviour, as well documents of other cases spanning three years, field observations, and interviews with PHIs and agencies serving clients who hoard. Legislation governing public health inspections was also examined. It was found that the PHIs at the SDHU respond to all health hazard calls they receive even though the HPPA is not clear that it is a requirement and not all health units in Ontario make site visits for these complaints. PHIs treat all clients professionally and compassionately

but do not always achieve resolution in these cases. This is as a result of (1) client factors such as advanced age, infirmity, living alone, with a lack of formal and informal supports; (2) health unit factors such as lack of training of PHIs in the area of hoarding and its psychological ramifications; (3) external factors such as the lack of affordable resources, the lack of follow-up, and the lack of coordination of services; and (4) factors inherent within hoarding behaviour such as the magnitude of cleanup required and the difficulty of halting the behaviour.

When intervening in hoarding cases a balance must be struck between the rights of hoarding clients and the rights of the family and community. In the case of animal hoarding, the rights of the animals must be pitted against the desires of the individual. Although the community has the right to be protected, coercion by regulatory bodies rarely leads to the successful conclusion of a hoarding case. More success has been achieved when multidisciplinary task forces approach hoarding from a combined social control and therapeutic position. Because of the time involved in treating hoarding behaviour, it may be necessary for agencies to advocate on behalf of hoarding clients for increases in funding to ameliorate some of the structural barriers that currently exist.

Recommendations for both the SDHU and municipalities within its catchment area have been provided that would improve the local response to hoarding with the most pressing need being the formation of a coalition that would create a coordinated and consistent response to hoarding cases. Since hoarding is more commonly found in older age groups, and the population in Canada is aging, the time to support a comprehensive solution to hoarding is now. The challenges *can* be overcome.

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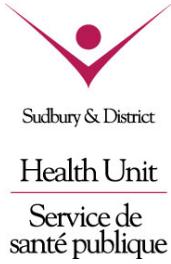
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## Appendix A



Sudbury & District Health Unit  
Service de santé publique de Sudbury et du district  
Resources, Research, Evaluation and Development Division  
Division des ressources, de recherche, d'évaluation et de développement  
1300 rue Paris Street  
Sudbury, ON P3E 3A3  
705.522.9200, ext. 350

## Memorandum / Note de service

To | À: Phyllis Montgomery, Laurentian University  
Suzanne Lemieux, RRED

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From | De: Michael King, Research Ethics Review Committee (RERC)  
705.522.9200, ext./poste 519 – kingm@sdhu.com

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Date: July 15, 2015

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Re | Objet:

### Statement of Approval

File #: 2015-01      Exploring the Environmental Health Division's response to potentially adverse housing situations involving vulnerable people

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Thank you for submitting the above research proposal for ethical review.

**DECISION: Approved.**

This project has been approved until May 31, 2017 and the study may now proceed. The final report is due May 31, 2017.

Please note that the RERC requires that you continue to adhere to the protocol as last amended and approved by the RERC. The RERC must approve any further amendments before they can be implemented. If you wish to modify your research project, please contact the RERC Committee outlining any changes to your proposal.

If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Adverse or unexpected events must be reported to the RERC as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of research.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and

approvals of those facilities or institutions are obtained and filed with their respective Research Ethics Board (or equivalent) prior to the initiation of any research protocols.

The Tri-Council Policy Statement (TCPS) requires that ongoing research be monitored. A final summary report is required for all projects. Researchers with projects lasting more than one year are required to submit a report annually.

Please quote your original RERC file number on all future correspondence. If you have any questions, please do not hesitate to contact me.

## Appendix B

### **APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS**

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New <input checked="" type="checkbox"/> / Modifications to project / Time extension	
<b>Name of Principal Investigator and school/department</b>	Phyllis Montgomery, Nursing, Suzanne Lemieux, SDHU
<b>Title of Project</b>	Public health's response to adverse housing situations.
<b>REB file number</b>	2015-08-03
<b>Date of original approval of project</b>	August 25, 2015
<b>Date of approval of project modifications or extension (if applicable)</b>	
<b>Final/Interim report due on: <i>(You may request an extension)</i></b>	Sept, 2016
<b>Conditions placed on project</b>	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, Laurentian University Research Ethics Board

## Appendix C

### Semi-structured interview Guides

#### Semi-structured interview guide for inspectors

How long have you been going out on this type of call?

- How many of these calls do you estimate that you have handled?
- Are you comfortable with these calls?
- Has the way that they are handled changed over that time? How so?

Do you think the SDHU should be involved at all? Why?

- Is there written policy? Can you tell me about it?
- Is there unwritten policy? Can you tell me about it?

Do you think this fits the mandate of the health unit? Why or why not?

- Are you limited by the mandate? How so?

Have the types of cases changed? Better/worse?

- How often do you see repeat cases?

Do you think that you are making a difference? How?

- Do you think that problems are being solved or do you think that conditions revert back?
- Explain.
- What would you differently if you could?

What do you think needs to be done in the community to better handle these cases?

- What would make your job easier?

How do you rate hoarding?

- Can you show me on the clutter scale what you often see?
- Where would hoarding start for you?
- Do you think that cases are closed when clutter situations are still unmanageable?

Do you feel that when you deal with these cases that you are really functioning as a social worker?

- Would a social worker be better positioned to do this type of work?

Is the health unit the first place that is called by agencies when they realize there is a problem?

- Is that because you have fostered such a good relationship with them?
- Is it because there is nowhere else for them to call?

Would you like to be able to do more?

Do you think it fits the mandate of the health unit?

Are there documents that you think I should look at that would help me understand?

**Semi-structured interview guide for social service agencies**

Does your agency work with a number of marginalized people who you feel may live in hazardous housing situations?

- Does your agency have a protocol for handling these cases?

Do you make referrals to the inspectors at the public health unit?

- Does the health unit contact you for assistance?

Does the health unit actually assist in the resolution of the problem?

- Do you think that it should be within their mandate? Why or why not?

Do you think that there needs to be a better coordinated response to individuals living in these situations?

- What would that look like?

Does your agency go into the homes of these individuals?

- If yes, is there a protocol that you follow when a worker feels that it is too dangerous to enter?
- Does this happen often?
- What do you do in these cases?

What would you suggest this community do to better respond to these cases?

**Semi-structured interview guide for hoarding participant**

Please tell me a story about your housing experience.

- How did this come about?

Tell me about some of the challenges you face.

- What is preventing you from being health?
- What is preventing you from keeping your home?

What do you find helpful?

Tell me about some of your supports?

- People?
- Things?
- Agencies?

Tell me about how you got involved with agencies or how agencies like the health unit became involved with you.

- Do you know why they are involved? Explain.

Tell me about a time in your life where you felt supported.

- What about a time when you didn't feel supported?

What would an ideal situation look like for you?

- With respect to housing
- With respect to supports

What can be done to better support you?

**Semi-structured interview guide for significant contacts of participants**

Please tell me a story about your experiences with \_\_\_\_\_ and his/her housing situation.

- Do you know how this came about?
- When did it start?
- Progression?
- Please explain.

From your perspective, what has prevented \_\_\_\_\_ from maintaining a healthy and safe home environment?

From your perspective, are there things that have assisted \_\_\_\_\_ in maintaining a healthy and safe home environment?

Do you know if your \_\_\_\_\_ used supports in attempting to remedy his situation?

- What kinds of supports?
- Please explain.

Do you know how your \_\_\_\_\_ became involved with services?

- Please explain.

What would an ideal housing solution look like for \_\_\_\_\_?

- What is required to help \_\_\_\_\_ in maintaining a healthy and safe home environment?
- What supports?

Do you have anything else to add?