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Factors Influencing Community Responses To Hoarding: Evaluating Operational Culture Of Hoarding Task Forces, Stigma, And Successful Outcomes

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Factors Influencing Community Responses to Hoarding: Evaluating Operational Culture of Hoarding Task Forces, Stigma, and Successful Outcomes

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Abstract

Hoarding is generally recognized as a pervasive need to acquire and retain items past the point of maintaining safe living spaces. Ushered into popular culture through television shows highlighting conflict, awareness of hoarding has increased. Experts report this condition affects 2-5% of the adult population, but this figure does not include children, family, neighbors, and community members (Buscher et al., 2013; Minor and Youth Children of Hoarding Parents, 2021). A unique feature of hoarding is the myriad of ways it is discovered." People who hoard may keep conditions a secret due to a lack of awareness, concerns about forced remediation, or recognition of societal stigma. As a result, first responders, neighbors, or adult protective service professionals may be the first to report unsafe living conditions. A way to coordinate proactive approaches to address community responses to hoarding is to establish a hoarding task force. Task force members can connect through the shared purpose of improving community health rather than code enforcement violations. The quantitative survey for this mixed methods study evaluated factors influencing the operational culture of hoarding task forces and measured levels of stigma. Interviews with hoarding task force members, family, and people with lived experience explored involvement and approaches to services, expectations, treatment, and definitions of success. Results indicated viable hoarding task forces have a stated purpose, regular meetings, educational offerings, a health and safety assessment, and opportunities for wraparound services. Holistic approaches that consider readiness for change and offer separate support for family members were also valued.

Acknowledgement

I began what I thought would be a decidedly personal journey to a PhD in community psychology in September 2019. However, in March of 2020 my two college-aged children, Kendall and Jay, returned from school to shelter in place while my husband, Jeff, a middle school assistant principal, managed remote learning from the dining room. My family became part of my PhD adventure in ways I had not expected because of the pandemic that spring, and I thank them for their continued love and support.

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Factors Influencing Community Responses to Hoarding: Evaluating Operational Culture of Hoarding Task Forces, Stigma, and Successful Outcomes

The general understanding of hoarding is as a pervasive need to acquire and retain items past the point of maintaining a safe living space. Ushered into popular culture through reality television shows highlighting conflicts around clean-outs, awareness of hoarding, stigma, and misinformation have increased. Originally classified as a mental health disorder and symptom of obsessive-compulsive disorder (OCD), Hoarding Disorder was reclassified in 2013 as a stand-alone diagnosis. Experts report this condition affects 19 million adults, or 2-5% of the population, but this figure does not include children, family, neighbors, and community members (Buscher et al., 2013; Minor and Youth Children of Hoarding Parents, 2021).

Because the most observable characteristic of hoarding is the prolonged inability to part with possessions regardless of the condition of or need for them, the disproportionate accumulation is often the first recognizable sign the person has an issue. (Scahill, 2019). People living with severe hoarding challenges may recognize their pathological collecting complicates daily activities, but place blame on external factors and resist intervention (Matthews, 2014). The American Psychiatric Association identifies this lack of insight as a criterion for diagnosis and specifies the need for community involvement, “If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities)*”* (APA, 2013, Table 3.29).

The volume and disordered nature of belongings, however, is just the visible tip of the iceberg. Below the surface is an unhealthy perfectionism and extreme attachment to the piles of possessions. People with hoarding difficulties may demonstrate sentimentality, creativity, and exceptional generosity with items while also needing them as a coping strategies. They

experience distress at the thought of letting go of items and struggle with sorting and decision-making. Unfortunately, as the cycle continues, the ability to maneuver around long dormant piles of belongings impacts health and well-being for everyone involved (Matthews, 2014).

Overview of Hoarding

As compared with OCD, people living with hoarding difficulties often lack awareness of their challenges (Tolin, Frost, Steketee, & Fitch, 2010). This lack of insight translates to reduced urgency about the piles of possessions. Indecisiveness and avoidance compound the problem until the person can no longer safely perform daily activities in their home. While hoarding behaviors may begin in younger years, they increase significantly with age and have similar presentation across race and ethnicity (Samuels, 2008).

The compulsive nature of hoarding, previously classified with OCD, is often present with other mental health issues. Research demonstrates co-occurrence with anxiety, depression, and attention deficit-hyperactivity disorder (Tolin, 2011). People with hoarding challenges also demonstrate impulsivity and compulsive behavior around acquiring (Frost et al., 2013; Shoham et al., 2017). These compulsive actions run the gamut from picking up free items along the side of the road, to superfluous on-line orders, or thrift store shopping.

Despite the need to gather and keep more belongings than necessary, research has not confirmed a link between severe hoarding tendencies and previous events involving material deprivation (Landau et al., 2011). Research does, however, demonstrate a connection between accumulation tendencies and prior trauma or life stress (Landau et al., 2011). More investigation is needed to determine how to use this information to inform treatment.

Symptoms

As previously mentioned, the first visible symptoms of severe hoarding challenges are patterns of excessive acquisition and difficulty discarding items, including those that are no longer useful or in good condition. A person who hoards experiences anxiety at the thought of releasing things, even if it means limiting activities in daily use areas like the kitchen or bathroom. Ironically, a person who hoards may also demonstrate tendencies of perfectionism around where to put things and not wanting others to touch possessions (Burgess et al., 2018). The urge to resist getting rid of things becomes compulsive in the manner of ritualistic behaviors with OCD (Vilaverde et al., 2017). Because the piles of clutter limit use of living spaces, a person who hoards may withdraw from family and friends.

Besides symptoms associated with acquisition and discarding, people living with hoarding behaviors also demonstrate anxiety about needing items in the future. Research has identified hoarding behaviors with anxiety, mood, and substance use disorders (Tolin, 2011). Executive function and attention challenges shown in people living with severe hoarding challenges are consistent with attention deficit-hyperactivity disorder (ADHD) (Tolin, 2011).

The primary reason a person living with hoarding disorder rarely seeks treatment without help is diminished insight into their condition (Park et al., 2014). Because of this lack of insight into the consequences of their behavior, family members, professional organizers, mental health professionals, and other community departments such as police, fire, social work, and inspectors for public health, may have to remedy the situation when the living conditions become unsafe (Bratiotis, 2013). The lack of awareness persists despite the potential for injury, isolation, and financial difficulties because of the volume of items (Nakao & Kanba, 2019).

Because people living with hoarding disorder rarely seek treatment for hoarding, their behaviors become entrenched by the time they receive assistance and extreme patience is necessary (Ayers et al., 2010; McGuire et al., 2013). Ample time is necessary to undo years of accumulation and regain trust. Sometimes a person who hoards will reach out to a professional organizer for help with perceived organization challenges. If possible, the professional organizer should encourage the client to contact a therapist for additional insight into their behaviors (Belk et al., 2007).

Diagnosing Hoarding

When a person who hoards makes an appointment with a counselor or medical professional, it is not generally for their hoarding behaviors, but for ADHD, anxiety, depression, or other symptoms related to an underlying medical condition (Kress et al., 2016). This presents unique challenges for medical professionals because 75% of people with Hoarding Disorder (HD) demonstrate comorbid mental health conditions, as well as symptoms of other chronic medical conditions (Kress et al., 2016). Even if a person receives a diagnosis of hoarding disorder, regular OCD or anxiety clinics may have limited options or be unable to provide extended home visit sessions to address the volume of clutter (Mataix & De LA Cruz, 2018)

The rate of medical illness among older adults living with symptoms of hoarding is significantly higher than that of their non-hoarding peers (Ayers et al., 2014). Lack of insight about daily self-care needs may contribute to decreased rates of visits to a physician and an increase in complications with medical problems such as diabetes or cardiovascular issues. As a result, emergency medical professionals may be the first to become aware of the hoarding when they respond to a medical health emergency in a packed home.

Rating Scales and Treatment Options

Because it is difficult to describe the overwhelming volume of items objectively, researchers created the *Clutter Image Rating Scale (CIR)* using photos to help family and other professionals working with hoarding behaviors rank levels of clutter (Frost et al., 2008) (Appendix A). Those using the scale select the photo that best matches the level of disorder in different rooms. The scale enhances the accuracy of categorizing the volume of the piles of belongings for a person with hoarding disorder who lacks awareness. This scale can help identify the severity of hoarded living conditions or provide insight for others about how to safely approach cleaning.

Concern about measuring family stress surrounding the complexities of hoarding led researchers to develop measures to report levels of impact, clutter, and learning new coping skills. The *Family Impact Scale for Hoarding (FISH)* assesses the level of family impact of hoarding (Nordsletten et al., 2013). Family members manipulated into avoiding conflict, may accommodate the behaviors of the person who hoards. This scale measures the degree of disruption (Nordsletten et al., 2013). The *Family as Motivators (FAM) Training* was designed to empower family members of people who hoard (Chasson et al., 2014). The five family representatives who completed the training demonstrated an increase in coping skills and hope (Chasson et al., 2014).

A person living with this mental illness may feel well-intentioned and loving, yet often creates an unintended climate of abuse–verbal, emotional, and physical for the children living in the home. Childhood distress is heightened, and families demonstrate increased stress (Tolin 2018). Research has consistently determined that information is needed about the consequences of growing up in a hoarded environment with a primary caregiver who hoards (Buscher et al.,

2013; Nakoa 2019; Nordsletten et al., 2013; Rees et al., 2018). The *Hoarding Rating Scale Interview (HRSI)* assesses features of compulsive hoarding (Tolin, 2010). Professionals can assess the level of risk of living in a hoarded environment using a Hoarding Rating Scale to assess clutter, difficulty discarding, excessive acquisition, and the intensity of distress and impairment caused by hoarding (Tolin, Frost, & Steketee, 2010).

Despite the negative consequences of living with clutter, people who hoard often resist treatment which creates frustration for family members. Researchers frequently report this resistance to treatment as "patient rejection attitudes" (Tolin et al., 2008). As a result, there is not a clear path to symptom management. More consideration is needed in the following areas: prevalence and cost of illness; improving detection and reducing stigma; treatment development; service development; and development of legislative frameworks to address pathways to treatment of symptoms for this complex disorder (Mataix & De La Cruz, 2018).

Because people living with hoarding challenges lack insight, traditional therapy approaches may not be considered. *Buried in Treasures Workshops* are an opportunity for a person living with hoarding disorder to gather with others for encouragement and to gain understanding of their behaviors (Frost et al., 2012). Based upon the *Buried in Treasures Workbook*, these support group style workshops provide a supportive environment for people who have too much stuff to challenge and change their habits. Focused on acquiring patterns, the workshops are highly structured and short-term (Tolin, et al., 2014). An update of this program because of the Covid-19 pandemic, was the increased opportunity to participate in virtual support sessions.

Another potentially effective method of intervention for people with hoarding disorder is Cognitive-behavioral therapy (CBT). This option has been used to target disruptive behaviors in

a variety of mental health disorders and has demonstrated potential for promising results with hoarding behaviors when follow-up visits are frequent (Tolin et al., 2015). CBT, with or without medications, can help with distress over getting rid of items when the person who hoards participates in the treatment (Scahill, 2019). Because research has demonstrated that people living with severe hoarding challenges are more likely to have experienced a traumatic or stressful life event, CBT is a helpful method for desensitizing the emotional triggers for this aspect of their challenges (Landau, 2011). Chou, et al., 2020, acknowledged CBT as the current standard, but found some effects limited and examined the use of Compassion-Focused Therapy (CFT) as a follow-up.

Another type of treatment is a process of approaching belongings to prioritize safety identified as a *Harm Reduction* approach (Tompkins, 2011). This approach begins with working with the person who hoards to identify and agree upon areas that are unsafe. This is followed by making decisions about the items in an unsafe area of the home. This intervention is most often implemented with a family member or paid professional and requires training. The training is vital, and the family members, professional organizer, or other practitioner must become skilled at employing the interview techniques (Carpenter et al., 2014). Measured patience is required so as not to challenge, "Why would you want to keep that?*"* or threaten to throw everything out, causing the person living with hoarding disorder to backslide. If a family member implements the treatment, they may feel the need to keep the intervention a secret not wanting authorities to discover the hazardous conditions while making consistent progress.

Treatment Considerations

One treatment consideration for people living with hoarding disorder is to address co-occurring mental health conditions. As previously mentioned, research has demonstrated

underlying attention deficit-hyperactivity disorder, depression, and anxiety (Tolin & Villavicencio, 2011). In addition, research suggests categorization problems pertaining to economic reasoning and owned items (Tolin & Villavicencio, 2011). Addressing these issues may help provide insight into hoarding behaviors.

A type of treatment intervention useful for an older person who hoards is not getting rid of belongings, but of making the environment safer (Tompkins & Hartl, 2009). An older individual may not change their established hoarding patterns but can agree their environment is not optimal. A family member or professional can encourage a person who hoards to consider what might happen if an Emergency Medical Technician needed to enter through the front door to provide emergency care. This approach requires that the family representative or professional overlook the way the clutter *looks* to focus on where the clutter is the most *unsafe*. Because this approach involves looking at the daily living spaces such as the stovetop, bathroom access, and tripping hazards, it is appropriate to consider in tandem with a therapist (Bratiotis et al., 2016). The person assisting categorizes items with permission or containerizes them in more out-of-the way area of the living space to control the hazards without broaching the subject of getting rid of belongings.

Effect on Family

While further investigation is needed on the behaviors and treatment of a person living with hoarding disorder, it is also necessary to consider the impact on family members. Hoarding is associated with household dysfunction, yet little research is available about the effect family members and the person living with severe hoarding challenges have on each other (Vorstenbosch, 2014). Caregiver burden has been recognized by researchers as detrimental and

the level of burden associated with family member stress is similar or higher than caring for a loved one with dementia (Drury et al., 2014) (Tolin, 2008).

The intensity of attachment to belongings has a disruptive effect on the quality of life of the person who hoards, and the family unit (Buscher et al., 2013). The accompanying lack of insight leads to additional distress over conditions in the home. For example, even in situations where the person who hoards agrees to address the problem, the phenomenon of churning items back into the space rather than releasing them often occurs (Drury et al., 2014). This inability to follow through aggravates the situation and further extends the timeline on attempts to create safer surroundings. The needs of the entire family and their patterns of interaction must be included when addressing approaches to remedy the situation (Alexanderson & Näsman 2017).

The lack of readiness for change is a challenging aspect of the disorder because of the repercussions on those around them. Even when a person who hoards acknowledges the impact of their behavior as problematic, they are rarely ready to enact lasting change without additional motivation and support. (Ayers et al., 2018). In addition, there is often an absence of a standard system of support, so family members are unsure where to turn for assistance (Bratiotis et al., 2016). If the person who hoards does not recognize the need for treatment, it can be challenging to engage a therapist or professional organizer even if they are trained in the less intrusive *Harm Reduction Approach* (Tompkins, 2011).

Buscher et al. (2013), identified three themes related to family stress around a family member living with hoarding disorder: the impact on the quality of life, the shattering of the family unit, and the tendency to accommodate or “rally around” the loved one who is hoarding. The stress surrounding a family member living with hoarding disorder can lead to negative

feelings toward the person who hoards, feelings of loss, and internal conflicts (Sampson, 2012). More support for adult children of hoarders is needed from professional support networks.

As previously mentioned, family members may use appeasement strategies to reduce conflict by not causing anxiety or anger in the person who hoards. Close significant others, such as romantic partners, are more likely to engage in these types of behaviors (Vorstenbosch, 2014). While this may mediate conflict in the moment, it does not help treat the underlying issues (Vorstenbosch, 2014).

Whether they grow up repeating the hoarding behavior, fail to launch and remain in the home, or establish boundaries in their adult lives, children of people with hoarding disorder may still be responsible with caring for their elderly parent or parents (Wilbram et al., 2008). As compared to caring for a family member with dementia, for example, the adult child has the added complication of a lifetime history of tending to their loved one in a challenging, cluttered environment. This exacerbates difficulty of providing care for the person who hoards, compounded by the expense of the clean-out, and internal conflicts over whether to contact Adult Protective Services (APS) (Sampson, 2012).

Children of People with Hoarding Disorder

Having a parent with a mental illness places a child at an increased risk of developing mental health issues (Reupert et al., 2012; Rees et al., 2018). Living with severe hoarding challenges reduces a parent's ability to appreciate the needs of the child and they may not provide an appropriate level of care. The impact of this developmental trauma and neglect must be understood if the child is to receive timely intervention (Brodin, 2011). This is illustrated in a self-report from an adult child of a person with hoarding disorder:

> *She was not overtly mean or vicious, and it took a lot of therapy for me to understand that toxins delivered with either a smile or a fit of tears are nonetheless toxic, that manipulation with guilt counts as emotional abuse just as much as screaming and hateful words, and that the dangerous physical circumstances of a hoarded environment count as physical abuse just as much as being smacked across the face* (Julia, 2019, Voices of COHPs).

Because the person living with hoarding disorder can be overwhelmed with anxiety and obsessive behavior about belongings, children living in the home may be forced to assume the role of caregiver for themselves. The child may attempt to manage outside relationships and establish boundaries for outsiders sensing their own caretaker cannot (Blake-Homes, 2019). Caregivers with hoarding disorder may not allow their child/ren to demonstrate autonomy, while also being unable to meet the child's basic needs. With this inconsistent parenting, the child may come to school or other activities unprepared and not properly groomed because of an inability to function within the disordered home environment.

The lack of a nurturing environment affects the child's sense of self (Hoffer, 2017). When a primary caregiver who hoards feels challenged or overwhelmed, their anxiety and distress may cause them to lash out at the child. They may blame the child for the conditions, complaining they do not help clean-up after eating, for example, when the environment is too chaotic for the child to know where to begin. The child lives with this underlying hostility, trying to appease the parent in unrealistic ways to avoid a confrontation.

Additionally, the more extreme the conditions in the living environment, the greater the risk for health problems such as asthma from dust around the excess, poor sanitation, improper care of pets, hazards such as tripping and falling, and malnutrition stemming from a lack of

proper food storage and preparation. In a 2017 study about patient secrets, Hoffer reported that kept secrets lead to a potential for lack of intimacy from the long-term burden of the experience. Secrecy around hoarded environments coupled with observing the parent's attachment to belongings over people exposes the child to ongoing emotional distress. In a study about health problems in young people exposed to childhood violence, Thoresen et al. (2018), reported a breakdown in feelings of connectedness to others directly results from living in an unhealthy, restrictive atmosphere. A study of social isolation found isolation and shame can follow children into their adult years impacting their ability to forgive and making it more difficult to have a relationship with the parent or caregiver (Stackhouse, 2016).

Hoarding is also associated with a social isolation for younger family members who understand the embarrassment of having a friend see the living conditions in the home (Park, Lewin, & Storch, 2014). Participants in a study about parent mental illness revealed that as children they were aware of the stigma surrounding their parent's illness (Murphy, Peters, Wilkes, & Jackson, 2017). For children of parents with hoarding disorder, this is exacerbated by the behavior of the parent and the potentially hazardous living conditions that result.

Task Forces

A unique feature of hoarding is the myriad of ways it is "discovered." People who hoard often keep it a secret —out of fear of forced remediation, societal stigma, or a lack of insight or readiness for change. A first responder, neighbor, or adult protective services professional may be the first to report the living conditions. The lack of insight into the consequences stemming from the vast quantities of belongings and refusals often generates conflict when family and friends, or neighbors, try to intervene. Involvement is forced when the living environment reaches a crisis point. A way to look beyond the "crisis mode clean-out" methods of intervention

and coordinate proactive approaches for communities addressing compulsive hoarding is to establish a hoarding task force.

A task force is formed when stakeholders are brought together in strategic way to solve a problem or consider an idea. According to Wickesberg and Cronin (1962), a task force is essentially a team effort. It is a technique used to organize around a specific issue. Because members of a task force are recruited from within the same organization or interest area, they can define the problem and implement the plan of action (Moore & Kovach, 1988). Task forces can permit access to resources and allow agencies to bypass issues more efficiently (Brewer, Jefferis, Butcher, & Wiles, 2007).

Effective leadership of a nonprofit task force can promote learning and capacity for change, while also influencing others and improving innovation. Effective nonprofits have a statement of mission and values that provide consistent rationale for decision-making (Balser & McClusky, 2005). Considering leadership and organizational culture of a task force based on consistency of involvement, adaptability, and having a stated mission, can lead to more successful outcomes (Denison & Mishra, 1995). Previous research on strategic leadership encompassed both for-profit and nonprofit sectors without careful consideration of the differences of the problems being solved (Phipps & Burbach, 2010).

Proper leadership is a key component for a successful task force. Wickesberg and Cronin (1962, p. 112) identified four criteria for success:

- *Problems to be addressed should be project or task oriented.*
- *Projects should be acknowledged when complete.*
- *Projects should be addressed within a stated time frame.*
- *Projects should be addressed by professionals with appropriate skills.*

Hoarding Task Forces

Because task forces are a team effort, different departments implement a coordinated response regardless of how the hoarding comes to light. Members of a hoarding task force connect through the shared purpose of community health to meet the needs of people living with hoarding difficulties using a multi-faceted approach. Establishing a task force to address community responses to hoarding allows for flexibility as needs and members change (Wickesberg & Cronin, 1962). Coming together under the organization of a task force, allows them to track results of their efforts and adjust as necessary. Hoarding Task Forces provide an opportunity to build connections around creating a safe living environment, improving mental health outcomes, reducing stigma, and providing community education and training. Members of a hoarding task force may provide training and education that can reduce stigma, support proactive interventions, and address trauma for family members. A hoarding task force provides an opportunity for these professionals to work toward community-level change in responses to hoarding (Bratiotis, 2013).

In her 2012 comparison study of the organization of five hoarding task forces, Bratiotis determined hoarding task forces were often grassroots efforts and suggested future research on viability should include *leadership, financial support, primary functions, community presence, actions, and outcomes* (p. 252). Findings also suggested that offering a full range of services was necessary for this challenging clinical problem (Bratiotis et al., 2016). Because hoarding clients lack insight, mental health practitioners are often included but coordination with other disciplines is also important for managing the complex nature of hoarding (Bratiotis et al., 2016). A study of the City of Vancouver's Hoarding Action Response Team (HART) model from 2016-2018 revealed that despite client avoidance and limited resources most cases using this community-

based intervention model were successful (Kysow, K. et al., 2020). In the study, success was defined as clutter reduction and tenancy preservation (Kysow, K. et al., 2020). This definition did not include measurements of improvements in mental health.

Reframing hoarding task force approaches to compulsive hoarding to include resources for psychological well-being is necessary. Because hoarding clients lack insight, mental health practitioners are often included but coordination with other disciplines is also important for managing the complex nature of hoarding (Bratiotis et al., 2016). Hoarding task forces provide opportunities to coordinate this range of services (e.g., fire, public health, housing, and mental health) (Bratiotis et al., 2013). This coordination of treatment for monitoring a person living with hoarding difficulties is a proactive way to mitigate health and safety issues from the resulting quantity of belongings. Because her 2012 study was qualitative with a small sample size, Bratiotis suggested future surveys consider the viability of hoarding task force operations with a larger representative sample.

Sense of Community and Hoarding Task Forces

A psychological sense of community is the "perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what one expects from them, the feeling that one is part of a larger dependable and stable structure" (Sarason, 1974, p. 157). People who hoard and their family members may not feel similar to others and may in fact, feel stigmatized by society to the point of keeping the conditions a secret. Family members may be in conflict over how to remedy the behaviors. In the context of having hope for recovery, Stevens, et al., 2018, determined that both hope, and a sense of community predicted better chances for recovery and better quality of life. This need for sense of community is evidenced by the traditionally combative relationships

surrounding reactive, last-resort community responses to hoarding in the form of code violations and forced clean-outs.

McMillan and Chavis (1986, p. 9) defined a sense of community as "a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together." Having a family member living with hoarding challenges can feel isolating. A place to begin creating a sense of community for people living with hoarding disorder and their families may be to reduce to stigma in the managed community response with a consistent, mission-driven, and innovative team.

Hoarding Task Forces offer an opportunity to create a connection around better outcomes for hoarding in their communities. Meeting the needs of a person who hoards requires a multi-faceted approach over a prolonged period and includes professionals from a combination of occupations, departments, and fields. These hoarding task force professionals may receive clients through an intake process and refer as appropriate. A sense of community within a hoarding task force can mediate the psychological distress of hoarding difficulties (Terry, et al., 2019). Ideally, the hoarding task force process would follow the four aspects of McMillan and Chavis' (1986) Sense of Community dynamics: Membership, Integration and Fulfillment of Needs, Emotional Connection, and Influence. Hoarding Task Force members can become proactive in their community responses and go on to educate and guide other communities as they help families on the road to recovery.

Stigma

An additional factor to consider for working with people living with severe hoarding tendencies is the elevated level of stigma associated with the condition as compared to schizophrenia, for example (Chasson, et al., 2018). Labeling a person who hoards by their mental illness may contribute to resistance in seeking guidance (Corrigan, et al., 2005). The stigma, or secrets and shame of hoarding disorder cause the person living with these impulses, or their family members pursuing help, to feel deficient or damaged (Corrigan, et al., 2005). This results in less overall support.

Public stigma is the unfavorable reaction that the general population has to people with mental illness. Self-stigma is the judgement people with mental illness turn against themselves. Most of the research investigating the automatic stigma of mental illness stereotypes has focused on participant self-report (Sanden, et al., 2015). Research has demonstrated expressed hesitation around people living with mental illness despite an understanding of the community challenges (Bromage et al., 2019). People living with severe hoarding tendencies often experience stereotypes, prejudice, and discrimination from others, causing them to internalize societal stigma about hoarding. Framing stigma for mental illness as a social justice issue, in the same manner as prejudice against race, for example, may help provide the structural change needed to ensure those experiencing challenges, such as difficulties with hoarding, feel valued (Bromage, et al., 2019). The field of community psychology views stigma and self-stigma as social constructs that can undermine intentions of treatment (Corrigan, 2005).

Both public and self-stigma may be understood in terms of three components: stereotypes, prejudice, and discrimination (Corrigan & Watson, 2002). A stereotype is a rapid social judgement that may or may not be believed but is used to categorize a group of people or

behavior. Prejudice occurs when negative stereotypes are supported. Discrimination is the behavioral reaction to the prejudice (Corrigan & Watson, 2002). Traditionally, a label of mental illness automatically generates negative stereotypes. Additional considerations are that labels are internalized and can be ideological, expressed, acted upon, and deep (Link, Mirotznik, & Cullen 1991). As a result, people living with mental illness may learn to anticipate the rejection of others.

Community service providers may themselves harbor stereotypes about people who hoard, impeding their ability to successfully treat the issues. Helping a person who hoards live a meaningful life in their communities necessitates this shift in thinking to a focus on recovery, rehabilitation, and health, rather than the debilitating problems associated with the visible mess (Corrigan, 2005). This person-centered approach provides insights into the complex nature of hoarding difficulties (Orr et al., 2019).

Because society associates visible characteristics of hoarding with laziness, the level of clutter involved with hoarding behaviors is also stigmatizing. People who hoard may feel excluded and come to expect negative responses from others because of the extreme mess (Sanden et. al, 2015). This may also trigger “courtesy stigma” where family members are stigmatized by association because others perceive them as contributing to or permitting the squalid conditions (Sanden et al., 2015). Those who voluntarily associate with a person who hoards are assumed to be part of the atypical behavior. This stigma not only presents with friends and neighbors but also with community responders and mental health professionals.

Lastly, the words used to describe hoarding and hoarding disorder can be stigmatizing. This researcher is avoiding negative language such as, “filthy mess,” in favor of bias-free language, “overwhelming quantity,” to describe hoarded conditions. Of additional consideration

is the use of person-first or identity-first language. In some cases, using identity-first is considered appropriate, as in “deaf person” rather than “person who is deaf” (Dunn & Andrews 2015). Because “hoarder” has a more negative connotation in popular culture, this researcher has opted for the person-first, “person living with hoarding challenges” labeling, rather than the identity-first, “hoarder.”

Successful Outcomes and the Transtheoretical Model of Change

Of additional interest for this researcher, is the application of the Transtheoretical (or Stages of Change) Model to people living with hoarding challenges. A delay in readiness for change creates conflict with the timeline of remediation of health and safety violations which may impact beliefs about successful outcomes. This model runs contrary to the idea popularized by the negative messaging of the *Hoarding* and *Hoarding Buried Alive* televisions shows that the way to a neat and orderly life for a person living with hoarding challenges starts with a conflict-based clean-out (Chasson et al., 2018). In much the same way as Anurag Satpathy (2020) outlines positive change associated with oral health habits, applying the transtheoretical model to hoarding is worth consideration.

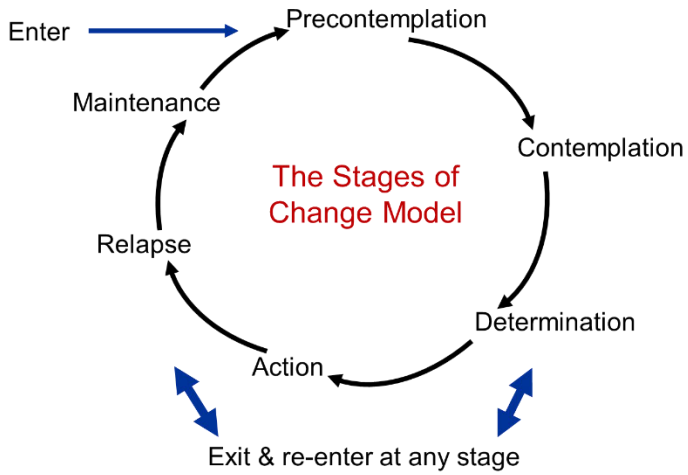
Lack of awareness of unsafe living conditions is a hallmark of hoarding disorder. This is consistent with the pre-contemplation or inaction phase of the transtheoretical model (Prochaska & DiClemente, 1982). The structured approach and positive promotion of habit changes of the model align with the shift in insight needed for people living with hoarding behaviors. Through a process that recognizes redefining definitions of successful results in terms of passing through stages, people with hoarding challenges build on each phase to a result that looks and feels different for each person.

The next stage of the transtheoretical model is Contemplation. This is the consciousness raising or self-awareness stage where there is an acknowledgment a problem may exist (Prochaska & DiClemente, 1982). This is comparable to patterns for people living with hoarding challenges who resist help with the clutter but start to consider seeking assistance with mental or other health issues or acknowledge safety concerns in the living environment. While they may not seek help for hoarding, they start to sense something needs to change.

In stage three, Determination, there is a commitment to change, while still considering what to do. The success may not yet be visible because it is internal. Stage four, the beginning stage of action, may be where visible change begins. The stages are shown in Figure 1 (LaMorte, 2019). On the way to maintenance, relapse or backsliding can occur. Proceeding through the process of changing hoarding behaviors with this model, has potential to redefine successful outcomes. It also illustrates why leaping to a full clean-out with expectations for maintaining a clean and organized environment during the precontemplation, contemplation, or determination phases is not realistic.

Figure 1

Transtheoretical Model of Change



Community Health Issue

Defined by Goodman, Bunnell, and Posner (2014, S60), community health is

> *a multi-sector and multi-disciplinary collaborative enterprise that uses public health science, evidence-based strategies, and other approaches to engage and work with communities in a culturally appropriate manner, to optimize the health and quality of life of all persons who live, work, or are otherwise active in a defined community or communities.*

Hoarding is a complex community health issue because remediation requires a multi-department, coordinated response depending upon the level of hoarding, decision-making capacity of the person with hoarding challenges, and well-being of other people living in the hoarded space. County and local governments become involved with hoarding cases to mitigate health and safety concerns caused by lack of insight, but an effective approach can be difficult to determine.

The Clutter–Hoarding scale® (2019) developed by the Institute for Challenging Disorganization (ICD) identifies five categories related to health and safety, pairing them with a scale of five levels of clutter (low, guarded, elevated, high, severe) to help professionals assess environments of people living with hoarding challenges.

- *Structure and zoning (low, guarded, elevated, high, severe)*
- *Animals and pets (low, guarded, elevated, high, severe)*
- *Household functions (low, guarded, elevated, high, severe)*
- *Health and safety (low, guarded, elevated, high, severe)*
- *Personal Protective Equipment (PPE) (low, guarded, elevated, high, severe)*

While these categories provide a framework for approaching the physical clutter, there are also mental health components, effects on family, and readiness for change to consider. Timpano et

al. (2009), raised concerns about the lack of attention to anxiety sensitivity and distress tolerance for people living with hoarding challenges.

Hoarding will be a community health issue for the foreseeable future. Reality television shows heightened awareness of hoarding challenges, but also exacerbated stigma (Chasson et al., 2018). County and local governments with a consistent approach and a variety of resources available for people living with hoarding behaviors and their families will be better equipped to mitigate health and safety issues and reduce mental health and stigma challenges that arise.

The intricacies of supporting families faced with addressing hoarding require a coordinated response. There may be resultant relationship problems and environmental challenges (Frost et al., 2010). When possible, it is best to focus on the issue from several angles–social workers are friendlier than code enforcement, for example (Bratiotis, 2012). Combining these various approaches helps address potential threats to public health and safety (such as fire hazards and falls) (Vilaverde et al., 2017).

In the first study of its kind, Frost et al. (2000), researched registered complaints about hoarding with health departments in Massachusetts. Neighbors of people living with hoarding disorder and city departments such as police and fire were most likely to make the complaints. For neighbors, the issue usually related to outdoor clutter (Frost et al., 2000). Though multiple agencies were involved in remediation efforts, departments of aging and fire departments had the highest level of involvement. Communities that employ case management strategies to coordinate their response, however, demonstrate more success in managing issues with hoarding (Bratiotis, et al., 2019). Related to this, a study of eviction found that 25% of people requesting housing assistance from a community eviction program met the criteria for hoarding (Rodriguez,

2012). Of these individuals, about half were receiving help for mental health issues (Rodriguez, 2012). Twenty percent had been evicted more than once.

Purpose of this Study

In a qualitative study of five hoarding task forces, Bratiotis 2012, reported hoarding task forces were dependent upon leadership, funding, founding purpose, and membership. Because many perspectives come into play with compulsive hoarding, the current study generalized the findings by considering the operational culture and viability (e.g., meeting needs, members involved for a long time, and hope for future) with a larger representative sample and semi-structured interviews of hoarding task force members. There is the perspective of the person who hoards, their family, societal stigma, therapist approaches, and safety needs enforced by community responders, among others. This current study evaluated the factors that impact the operational culture pertaining to current practices, leadership, psychological sense of community between hoarding task force members, and stigma around hoarding. Document analysis of hoarding task force websites was also conducted by the researcher to provide a more complete understanding of practices, policies, and operations.

Because an additional hurdle for people living with severe hoarding tendencies is the elevated level of stigma associated with the condition, items from Chasson et al. (2018) were used to consider levels and types of stigma (difference, disdain, and blame) held by members of hoarding task forces and experienced by family members and people living with hoarding challenges. Recent research defined insight-related challenges and considered the impact of readiness for change on the definition of successful outcomes (Ayers, et al., 2018). Interview questions exploring definitions of successful outcomes for people living with hoarding

challenges were included to better understand how community responders can meet the needs of people with hoarding challenges in their community for more successful outcomes.

Mixed Methods in Hoarding Research

Mixed method design for hoarding research was used in Murdock (2008)'s study of hoarding behavior in elderly women. A quantitative survey of adult-protective services workers was followed by qualitative study with more in-depth interviews. The explanatory-sequential design helped inform survey responses. Data from factor analysis was integrated with data from content analysis to help explain the tendency of the adult-protective workers to use mental illness to attribute symptoms of hoarding behaviors (Murdock, 2008). The current research proposes use of a similar design.

Phenomenological Approach

Research for this research study was conducted using a phenomenological approach. The viability of a hoarding task force, as described by members of a hoarding task force fits the definition of the phenomenological approach: to describe the lived experiences of individuals about a phenomenon as described by participants (Creswell & Creswell 2018). Articulating use of this approach is necessary for judging the soundness of the results (Garza, & Landrum 2015).

This two-phase mixed methods study began by collecting quantitative data from a survey sent to hoarding task force members. The survey was repeated in the second phase of the study to acquire more participants.

Characteristics of the data collected are summarized as follows:

- Practices and policies, operations, leadership, and viability (e.g., meeting needs, members involved for a long time, and hope for future) for hoarding task forces in the United States

- Types of beliefs (facets of stigma) held by members of hoarding task forces about people living with severe hoarding difficulties
- Including different perspectives (hoarding task force member, family member, or person living with hoarding difficulties) when defining successful outcomes for hoarding

The data obtained in two phases from the survey was then used to inform interview questions for qualitative data obtained in the second half of phase two. Interviews with people living with hoarding disorder, and family members of people living with hoarding disorder were included to further explore these factors. A characterization of the perspectives of those providing and receiving hoarding task force members is the main result (Creswell & Creswell, 2018).

This researcher also sought to ascribe meaning to the definition of successful outcomes for hoarding from the perspectives of the various stakeholders. Document analysis of hoarding task force websites, collected concurrently with qualitative interviews in the second half of phase 2, further clarified policies and procedures and considered availability of on-line resources for people seeking assistance, resources, and/or support.

Rationale

There is not a clear path to remediation of hoarding. Establishing a hoarding task force can be an effective and proactive way for communities to coordinate resources and educate others about hoarding while reducing stigma. An initial review of hoarding task force websites across the United States revealed inconsistencies in services provided, so it follows that each community should work with resources at hand, however exploring the differences in efficacy and perspectives of those utilizing and receiving services is helpful for communities seeking to implement or improve their own hoarding task force or community response. In addition, being

aware of the influence of stigma and reframing definitions of success can foster a sense of community among those impacted by hoarding.

Personal Biases

This researcher established a professional organizing business in December of 2010 and was an active member of the National Association of Productivity and Organizing Professionals (NAPO), NAPO's Chicago Chapter from 2010 to the time of the study. She is a former member of the Institute for Challenging Disorganization (ICD) and began participating in meetings with the Chicagoland Hoarding Task Force in the fall of 2021. In April of 2011, this researcher joined a team of volunteer NAPO Chicago members on an episode of a popular reality television show about hoarding clean-outs and went on to participate in two more episodes. She now considers the shows to be exploitative in nature but acknowledges they have raised awareness about the condition.

Additionally, this researcher receives periodic inquiries from concerned family members seeking assistance for a family member demonstrating hoarding tendencies. Most express frustration with their loved one's lack of insight and lack of affordable resources. When working with clients living with behaviors associated with hoarding disorder, this researcher choses environments identified as Level 1 or Level 2 on the Clutter–Hoarding Scale® (2019) and works alongside the client to make changes in daily living spaces rather than provide clean-out services (Tolin, Frost, & Steketee, 2010).

On several occasions working with hoarding clients (having also worked in the field of Early Childhood Special Education and obtained a Master of Education degree in Early Childhood Curriculum), this researcher grew concerned about the lack of assistance families received pertaining to the developmental and safety needs of children residing in the home. As a

result, this researcher connected with a representative from the Minor and Youth Initiative of the Children of Hoarders website (Children of Hoarders) and is currently participating in development of an icebreaker message for providers to help them talk about hoarding with young clients.

This researcher acknowledges biases in these areas and anticipates interest in what hoarding task forces are doing to protect and support minor children living in the home. These biases could also cause her to skew her interpretation of the data to enhance the role of professional organizers or the need for more understanding of the role of adult children raised by hoarding parents. Her direct work with people with hoarding disorder in a professional capacity, could also alter her analysis and presentation of the results.

Philosophical Perspective

Many perspectives come into play with compulsive hoarding. There is the perspective of the person who hoards, their family, stigma from society, the approach used by a therapist, and safety needs enforced by community responders, for example. This research study interpreted these multiple perspectives using quantitative and qualitative methods in a mixed method explanatory-sequential design. The constructivist perspective appropriately encompasses this approach because the researcher relied on the participant's perspectives to understand the research problem. (O'Donnell, 2012).

Research Questions:

1. Does having established practices and policies for a hoarding task force impact the viability of the hoarding task force for the long term?
2. What are the similarities and differences in reported strengths and challenges for hoarding task forces throughout the United States?
3. How do members of hoarding task forces who feel their task force has good leadership perceive their relationship with other hoarding task force members in terms of working toward similar goals and availability for each other when problems arise?
4. What are the similarities and differences in operations (regularity of meetings, financial resources, and availability of education/training) for hoarding task forces throughout the United States?
5. According to hoarding task force members, what are the most effective leadership skills for hoarding task force leaders for managing hoarding task force operations?
6. What effect does the department/field of a hoarding task force member have on their beliefs about people living with hoarding difficulties?
7. What relationship do hoarding task force or other community interventions have on beliefs about hoarding from the perspective of hoarding task force members, family member of a people living with hoarding challenges, and those living with hoarding challenges?
8. How does the definition of a successful outcome for hoarding differ between hoarding task force members and people living with hoarding challenges or family members of people living with hoarding challenges who have been the recipient of community intervention for hoarding?

Method

Mixed Methods

Mixed methods research design provides an organized way to utilize the strengths of qualitative and quantitative research, while also decreasing limitations of each. Mixed methods originated in the late 1980's and picked up steam in the 1990's (Creswell & Cresswell, 2018). In studies with a mixed methods design, quantitative and qualitative data integrate during the data analysis and interpretation. *The Handbook of Mixed Methods in Social and Behavioral Sciences* examined mixed methods for social and behavioral sciences and supported use of this comprehensive approach (Tashakkori & Teddlie, 2010). Since the publication of Tashakkori and Teddlie's (2010) handbook, additional journals have continued to encourage mixed methods research (Creswell & Creswell, 2018). Research questions for this study were examined by collecting both qualitative and quantitative data in a mixed methods research design.

Considering qualitative and quantitative research with a mixed method design allows for comparisons of different perspectives. Quantitative research focuses on quantifying data collected in a study, while qualitative research considers the qualities or inherent meaning. Collecting data through a quantitative survey and following up with qualitative interviews allows research questions to be analyzed more thoroughly.

Phase 1:

The small quantitative data sample collected during this researcher's Pilot Research Study was used as the data for Phase 1. Results demonstrated that participants may have hesitations about the level of success of the work meeting the needs of people with severe hoarding difficulties in their community. Because the survey could not determine the inherent meaning behind the responses, the researcher could not conclude reasons for this hesitation.

Following the quantitative survey with a Phase 2 of qualitative interviews allowed participants to share more about beliefs and successful outcomes. The addition of a Phase 2 of quantitative survey distribution expanded upon the number of participants to improve validity of the results.

Explanatory Sequential Mixed Methods Design

The first consideration for this mixed methods study was use of a one phase convergent design (Creswell & Creswell, 2018). This approach allows the researcher to collect and analyze both quantitative and qualitative data but expects the data to show similar results. Because this researcher was looking for further explanation of quantitative results through qualitative data, this design was not the best fit. Although analysis of the archival data may have supported the quantitative results, the interviews elaborated on the survey results. Additionally, the three-phase exploratory-sequential design was not appropriate because the researcher started with quantitative surveys and was not testing a new measure in the quantitative phase.

This study used the two-phase approach of the explanatory-sequential mixed methods design (see Figure 2). The number of participants limited the survey data collected from Phase 1, however, the data revealed patterns that helped to inform the design. Data from surveys of additional participants was collected in Phase 2 and added to quantitative data results from the Phase 1. Interviews of participants meeting the selection criteria and questions based upon analysis of the first phase were used for the second, qualitative phase. Document analysis was layered in as an additional qualitative measure to further support or refute the quantitative data results. The researcher analyzed the quantitative and the qualitative data independently. The survey data, interview questions, and document analysis were then integrated.

Figure 2

Explanatory-Sequential Design (Two-Phase Design)

Seeking to interpret multiple perspectives using quantitative and qualitative methods employing a constructivist worldview, a phenomenological approach with a mixed method explanatory-sequential design was used to provide a lens for analyzing the results. The researcher added validity to the results by triangulating the data sources. Quantitative and qualitative data were analyzed separately to look for coinciding themes. Detailed descriptions of how the qualitative interview and document analysis data explained the quantitative survey data provided deeper understanding and further validated the results.

Ethical Considerations

An indispensable component of research is an ethical approach. Participants were aware that their engagement was voluntary, and they completed an informed consent process that included affirming their desire to participate with a signature. Participants who identified as having a lived experience of hoarding disorder were recruited through their attendance at an annual hoarding conference hosted by the International Obsessive-Compulsive Disorder Foundation, or via social media platforms run by the researcher's professional organizing business. This demonstrated intention from the person with lived experience to be actively seeking support and education for their hoarding challenges. Care was taken to structure interview questions using person-first language.

The researcher followed the ethical standards prescribed by the National Louis University Institutional Review Board. Participants were informed about the nature of the study and that they were all volunteers who could withdraw at any time. Benefits of study outweighed the risks and were no greater than would be encountered in real life. The researcher was cautious about the sensitive nature of the topic of hoarding and resources were offered to family members and people living with hoarding challenges during their interviews. Participants were informed that the purpose of the study was to explore the differences in efficacy and perspectives of those utilizing and receiving community services for hoarding.

Quantitative Data Collection: Phases 1 and 2

Participants

Data from the 20 Phase 1 participants was added to data from 13 additional on-line survey participants collected in Phase 2. All participants of the on-line survey were members or referral partners of a multidisciplinary hoarding task force and included social workers, therapists, an attorney, residential relocation specialists, professional organizers, and representatives from adult protective services and other public health fire and code enforcement departments.

The thirty-three survey participants were members of multidisciplinary hoarding task forces from 11 states in the United States (Reported: Arizona, California, Illinois, Massachusetts, Michigan, Minnesota, Montana, Ohio, Texas, Washington, and Wisconsin.) Professional job titles reported were an assisted living case manager, administrative analyst, collaborative community planner, an enforcement director, fire inspector, forensic manager, health inspector, social workers, therapists, mental health experts, private practice owners, professional

organizers, program managers, a realtor, senior environmental specialist, and other senior liaisons. The participants were not asked to specify age or gender.

Recruitment

Internet searches were used to locate additional hoarding task forces around the United States. Contact was established via public emails listed on hoarding task force websites or other documents publicly available on-line such as a PDF list of active members. When emails were not available, contact was made via publicly available telephone numbers to obtain permission for email contact. It was up to the discretion of the contacts whether to complete the survey and/or encourage others to do so as well.

The researcher was invited to join a private Facebook Group, *Hoarding Task Force Network,* and recruited participants there as well as through the Institute for Challenging Disorganization and the National Association of Productivity and Organizing Professionals (NAPO)'s Productivity & Organizing Interactive Networking Tool (POINT) community via the Hoarding Special Interest Group. Additional contacts were established via a snowball sample of convenience using the researcher's social media platforms.

Procedures

Data was collected from March 2021 – April 2021 (Phase 1) and November 2021 - December 2021 (Phase 2). An on-line survey requested information from the hoarding task force member participants about the practices/policies, operations, leadership, and viability of the organizational culture of the participants' hoarding task force.

Instruments

Demographic information for the on-line survey of hoarding task force members was obtained using open and closed-ended questions. Items included education level, job title, how

many years on the hoarding task force, and whether participants have a friend or family member challenged by hoarding difficulties.

Items were adapted from case study results from Braitiotis (2013) of Community hoarding task forces: a comparative case study of five task forces in the United States. In addition to these items, an edited version of the Sense of Community Index (SCI-2) was used to further identify information in these areas. Items on the SCI-2 were edited to directly apply to hoarding task force respondents. For example: *This community has been successful in getting the needs of its members met*., was edited to: *This Hoarding Task Force has been successful in meeting the needs of people living with severe hoarding difficulties in our community*. Three items from Chasson et al. (2018) were used to identify types and level of stigma believed about people living with hoarding challenges.

Bratiotis (2013) considered the uniqueness of demographics, resources, and service delivery systems when considering her design and sample for the five task force sites in her comparative case study. This study also considered the demographics of the hoarding task force communities. Five open and close-ended demographic questions were used to evaluate the department/field of members and referring agencies, length of time as a member or referral partner, and whether time spent is compensated or donated, and years of education.

To identify characteristics of the operational culture of participants' hoarding task forces, the researcher created an 11-item survey about practices/policies, operations, and leadership. The researcher adapted these items from the sub themes of three themes identified from Bratiotis's (2012) research, "Community hoarding task forces: a comparative case study of five task forces in the United States" (Bratiotis, 2012). Themes considered were:

1. Task force formation and operation

2. Practices and policies of task forces

3. Long-term viability of hoarding task forces.

Bratiotis supported these themes and sub themes with direct quotes (2012).

The Sense of Community Index 2 (SCI-2)

The original version of this scale was used with modification to assess perception of the four elements of a sense of community: membership, influence, meeting needs, and a shared emotional connection. McMillan and Chavis (1986) initially created The SCI as a four-dimension model based on four factors: membership, influence, integration, fulfillment of needs, and shared emotional connection. Although the SCI was a strong predictor of these behaviors, the 24-item scale was developed and revised due to low subscale reliability into Index 2 which uses a Likert scale demonstrated to be more reliable (Chavis, Lee, & Acosta, 2008). The SCI-2 is a reliable measure (coefficient alpha= .94). The items selected for use were relevant to the three themes that resulted from the Bratiotis (2012) study.

Stigma Measure

Three items were provided to the researcher by Dr. Chasson for inclusion in this study. Participants were asked to rate hoarding disorder (HD) on difference facets of stigma: difference, disdain, and blame (Chasson, et al, 2018). In Chasson's (2002) original measure, three conditions were measured: severe mental illness (SMI), have been in jail, and hoarding disorder (HD). The three HD items were provided to the researcher by Chasson for inclusion in this study. Example item from *difference* facet: *How similar do you think a person with hoarding disorder is compared to everyone else in the general population*? Participants were asked to rate the item on a Likert scale from 1-9, with one being *very similar* and nine being *not at all similar*. Internal

reliability estimates for the derived difference and disdain scores ranged from .60 to .86 (Chasson, 2002).

Qualitative Data Collection

Participants

The fifteen interview participants were comprised of five professionals who work with people living with hoarding challenges and are members of a hoarding task force, five who were family members of a person with hoarding challenges and have considered or been involved with community assistance for hoarding, and five who identify as having hoarding as a lived experience with varying degrees of experience with community resources. All five professionals who worked with people living with hoarding challenges were also participants from one of the two phases of quantitative data collection.

Three men (20%) and 12 women (80%) participated in the interviews. The ages of the participants ranged from 30 to 72 years of age. Participants represented Arizona, California, Illinois, Michigan, Montana, New Jersey, Ohio, Tennessee, Washington, Washington DC, and Wisconsin. Overall, the hoarding task force member participants were older than the family members and participants with hoarding challenges and the hoarding challenged participants had the largest range in age.

Table 1

Age ranges of Interview Participants by category

Age range	N	HTF Members	Family Members	Hoarding Challenges
31-40	6		3	3
41-50	3	1	2	
51-60	2	1		1
61-70	3	3		
71-80	1			1

The five hoarding task force members reported working in the fields of social work, professional organizing, relocation, and home support. Three were the founders of their hoarding task forces and two others became involved as a "*natural fit*" or interest.

> "*We deal with relocation of folks through eminent domain or code enforcement so my supervisor thought it would be a natural fit for myself and my coworker, who is also relocation specialists to be part of the group.*" (HTF2)

> "*I was interested in it because my dad's a hoarder. Or was a hoarder.*" (HTF3)

Four of the five family members reported a hesitancy to speak to others about their family member with hoarding challenges and appreciated the opportunity to share their stories in the confidential space of a research interview. The fifth family member had spoken publicly on numerous occasions. Of the five participants with hoarding challenges, two reported also having a parent with hoarding challenges and four of the five reported becoming aware of hoarding because of depictions of people with hoarding challenges in the media.

Recruitment

Participants of phase one and phase of the quantitative portion of this dissertation research study were asked to indicate if they were interested in participating in future research. The names of those who expressed interest were collected in a spreadsheet and participants were contacted to determine if they would consent to be interviewed.

In addition, attendees of the International Obsessive Compulsive Disorder Foundations' Hoarding Conference entered contact information on a spreadsheet indicating interest in being contacted by other conference attendees. On the spreadsheet, attendees were asked to indicate whether they had lived experience with hoarding, were a family member or supporter, or whether they were a professional. This researcher attended the conference and used the list to contact

potential interview participants with lived experience who attended the conference, as well as family members or supporters. If they previously contacted or received assistance from a hoarding task force member or referral partner, or other community support, they were eligible for the interview.

The initial plan was to recruit only participants served by hoarding task forces, but confidentiality factors and lack of access to information about those served by hoarding task force precluded this option. The criteria were then expanded to include interaction with a variety of community resources.

A snowball sample of convenience via the researcher's social media platforms was also used to locate participants. Because the researcher had established trust via the TikTok platform, several participants reached out to express interest following their interaction with the researcher’s recruitment posts. It was up to the discretion of the contact whether to participate in the interview.

Phase 2 (interview) Procedures

Interviews were conducted from 12/2021 - 3/2022. Participants were interviewed separately via web conferencing software (Zoom). The researcher prepared an interview protocol as a guide for the interviews. The protocol contained basic information about the interview, an introduction, opening questions, content questions, potential probes, and closing questions (Creswell & Creswell, 2018). The interviews were audio and video recorded. Each interview lasted approximately 45 minutes and the researcher took notes in addition to following the protocol. Participants were given the option to further protect their identity by not having their camera on.

Websites were “interviewed” by the researcher during the month of March 2022. The researcher visited individual websites and recorded responses to questions in a spreadsheet. Because this public data was available on-line, the analysis could be completed at the researcher’s convenience.

Semi-structured Interviews

An interview protocol was developed for this study based upon analysis of the quantitative data. It contained a total of 12 semi-structured and three demographic questions. Questions similar in content and order were asked of hoarding task force members, family members, and those with lived experience. The interview items asked about experiences and expectations receiving assistance for hoarding. The items also requested information about best practices and treatments for supporting a person living with hoarding challenges, how to define successful outcome, and positive attributes of having these challenges.

Interview Questions

1. *How did you become involved with the hoarding task force in your community? (How did reaching out to a hoarding task force as a family member / supporter affect your approach to services for your family member / friend living with hoarding challenges? When did you first understand your family member/you had hoarding challenges?)*
2. *What is your department or field? Job title?*
3. *How did being a (insert department/field/job title_____) shape your approach to helping this person/people with hoarding challenges? Do you draw on your prior experiences as (department/field/job)?*

4. *What have you learned about outcomes for people living with hoarding challenges?*
5. *Have your expectations changed since you first started?*
6. *What can you share about the role of family members in supporting a person who hoards?*
7. *There are different levels of hoarded environments and various physical and mental health conditions can also be associated with hoarding disorder, how does this affect the outcome in your situation?*
8. *What have you learned is the most effective treatment for hoarding disorder?*
9. *What are the criteria for success with hoarding?*
10. *How would you suggest addressing someone who is refusing help from a hoarding task force?*
11. *What are some positive attributes of having hoarding disorder?*
12. *Is there any information you would like to add that you feel is important for this researcher to know about your experience with hoarding outcomes?*

Demographic information:

- *Which category does your age fall into?*
- *Current Employment*
- *Location of hoarding task force referenced in questions above (state)*

Qualitative Data Analysis

The researcher transcribed and reduced the transcript size of the 15 interviews by eliminating non-essential information before analyzing. Interviews were read for a general overview and organized for coding. The researcher began the process of assigning descriptive

and thematic codes following Tesch's Eight Steps of coding (Creswell & Creswell, 2018). Coding software (Quirkos) and printouts of the transcripts were used to makes use of benefits of each type and view the data from different perspectives. The coding software created immediate customized reports to cross-reference with the printouts. The researcher identified emerging themes, then organized and combined them to explain the essence of the data. The data were further reorganized to identify relationships between the categories and subcategories.

Document Analysis

Document analysis was layered in as an additional qualitative measure to further support or refute the quantitative data results. As part of this process, the researcher gathered information from publicly available websites for hoarding task forces across the United States. This shareable resource can be found as Appendix A. The researcher then analyzed 13 hoarding task force websites around the United States using yes/no closed-ended criteria.

Results

Quantitative Data Analysis

Research Question 1: Does having established practices and policies for a hoarding task force impact the viability of the hoarding task force for the long term?

Participants were asked to indicate whether their hoarding task force has a set of established practices and policies. Thirty-two of the 33 participants (97%) reported having a stated purpose for their hoarding task force. One participant (3%) indicated their hoarding task force does not have a stated purpose. For the item, *our task force has regularly scheduled meetings*, 31 (93.9%) hoarding task force members reported their task force has regular meetings.

Each of the 33 participants in the study responded to the item about whether their hoarding task force provides professional training/education programs. Five participants (15.2%)

reported that their hoarding task force does not provide professional training/education programs. Twelve participants (36.4%) reported their hoarding task force provides professional training/education programs, but the meetings were *temporarily suspended due to global pandemic restrictions*. When combined, the *yes* and *yes, but temporarily suspended* responses became 28 or (84.8%) of participants reporting that professional training/education programs were provided by their Hoarding Task Force (Table 2).

Table 2

Hoarding Task Force Practices

Practices	N %	N %
Stated Purpose	32 (97%)	1 (3%)
Regular Meetings	31 (93.9%)	2 (6.1%)
Training/Educ.	28 (84.8%)	5 (15.2%)

A chi-square calculation was performed to determine if these percentages were more than might be expected by chance. The results show a significant difference between participant responses and the number of responses expected by chance (see Table 3). This indicates that having a stated purpose, holding regular meetings, and providing education and training opportunities are specific characteristics of these hoarding task forces.

Table 3

Significance of Differences in Hoarding Task Force Practices

Hoarding Task Force (HTF) Practices			
	Purpose	Meeting	Education
chi-square	29.121[a]	25.485[a]	16.030[a]
Df	1	1	1
Significance	<.001	<.001	<.001

a. 0 cells (0.0%) have expected frequencies less than 5. The minimum expected cell frequency is 16.5.

Participants in the study also responded to an item about whether their hoarding task force interventions begin with a health and safety assessment. Eighteen participants (54.5%) reported that their interventions begin with a health and safety assessment. Twelve other participants (36.4%) reported *some of our members begin their interventions with a health and safety assessment*. The remaining three participants (9.1%) reported their interventions did not begin with such an assessment.

Modified SCI-2 Items: On a scale of four continuous choices, with one end being *not at all* and the other being *completely*, participants were asked whether members of their hoarding task force members *have similar priorities and goals for people living with severe hoarding difficulties in our community*. Sixteen participants (48.5%) selected *completely.* Seventeen participants (51.5%) chose *somewhat completely*. Zero participants selected *sometimes* or *not at all* (see Table 4).

On the same scale, participants were asked whether members of their hoarding task force have *been successful in meeting the needs of people living with severe hoarding difficulties in your community*. Three participants (9.1%) indicated a choice of *completely* and eight (40%) chose *somewhat completely.* For this item, 15 participants (45.5%) selected *somewhat completely*, and 1 participant (3%) chose *not at all* successful.

Participants were also asked if they expected to be a part of their hoarding task force community for a long time and whether they felt hopeful about the future of their hoarding task force community. Fourteen participants (42.4%) responded *completely* and 14 (42.4%) responded *somewhat completely* to expecting to be a part of the community for a long time. Twelve participants (36.4%) percent responded *completely,* and 15 participants chose *somewhat completely* to feeling hopeful about the future of the hoarding task force.

Table 4

Viability of Hoarding Task Force (HTF): Sense of Community Items

Sense of Community Items				
	Completely	Somewhat	Sometimes	Not at all
	N %	N %	N %	N %
Our HTF members have similar priorities and goals	16 (48.5%)	17 (51.5%)	0 (0%)	0 (0%)
I expect to be a part of this HTF community for a long time	14 (42.4%)	14 (42.4%)	3 (9.1%)	2 (6.1%)
I feel hopeful about the future of this HTF community	12 (36.4%)	15 (45.5%)	5 (15.2%)	1 (3%)
Our HTF has been successful in meeting needs of people living with severe hoarding difficulties in our community	3 (9.1%)	13 (39.4%)	15 (45.5%)	1 (3%)

The mean score for each item, *hoarding task force members have similar goals and priorities*, *I feel hopeful about the future of this hoarding task force community*, *I expect to be a part of the hoarding task force community for a long time*, and *our hoarding task force has been successful in meeting needs of people living with severe hoarding difficulties in our community* were 3.48, 3.21, 3.15, and 2.48 respectively (see Table 5).

Table 5

Means: Sense of Community Items on a 4-point Likert scale

Sense of Community		
	Mean	SD
Members have similar priorities and goals	3.48	.508
Hopeful about the future of this HTF community	3.21	.795
Expect to be a part of community for long time	3.15	.857
Successful in meeting needs	2.48	.834

For further comparison, a stepwise linear regression was used to eliminate criterion and identify possible predictors of *feeling hopeful about the future of the hoarding task force*. At each step, a variable with the lowest criterion was removed. Expecting to be a part of the task force for a long time was a significant predictor of feeling hopeful about the future (see Table 6).

Table 6

Predictor of Sense of Community Item Hopeful About the Future

Model	R	R Square	Adjusted Square	Standard Error of Estimate
1	.776[a]	.603	.590	.509

a Dependent Variable: Hopeful About the Future
b Predictors: (Constant), Long Term Commitment

Research Question 2: What are the similarities and differences in reported strengths and challenges for hoarding task forces throughout the United States?

Participants were asked to report strengths and challenges of their hoarding task forces from lists provided. The lists were based upon the reported sub themes from a 2012 study of hoarding task forces (Bratiotis). Sixty-five percent or more of participants reported strengths in

the areas of *Referral networks and/or resources* and *Education and training opportunities.* Only nine percent reported *funding* as a strength (see Table 7).

Table 7

Reported Strengths and Challenges of Hoarding Task Force

Item	N %	N %
	Strength	Challenge
Referral networks and/or resources	23 (69.7%)	9 (27.3%)
Education/Training opportunities	22 (66.7%)	6 (18.2%)
Communication across agencies	18 (54.5%)	12 (36.4%)
Member Expertise	18 (54.4%)	4 (12.2%)
Community Outreach	15 (45.5%)	4 (12.1%)*
Person who hoards is at the center of effort	9 (27.3%)	7 (21.2%)
Assessment	7 (21.2%)	7 (21.2%)
Leadership	7 (21.2%)	6 (18.2%)
Volunteers	6 (18.2%)	11 (33.3%)
Marketing and public relations	5 (15.2%)	13 (39.4%)
Funding sources for hoarding task force services	3 (9.1%)	**30 (90.9%)**

* The option of *Community Outreach* as a Challenge was inadvertently left off the survey during the first round of data collection, so this number is probably a lower reflection of the actual result.

To further analyze reported strengths of participant's hoarding task forces, a binary logistic linear regression was used to eliminate criterion and identify possible predictors of having a *person who hoards at the center of the effort*. At each step, a variable with the lowest criterion was removed (see Table 8). A strength of *having the person who hoards at the center of the effort* was predicted by having *assessment* and *good leaders* as a strength.

Table 8

Predictors of Reported Strength of Person Who Hoards at Center of Effort

Model		B	S.E.	Wald	df	Sig.	Exp (B)
Step1[a]	St. Assessment	2.526	1.000	6.379	1	.012	12.500
	Constant	-1.609	.548	8.634	1	.003	.200
Step2b	St. Assessment	21.890	13357.97	.000	1	.999	321E+9
	St. Leader	-21.197	13357.97	.000	1	.999	.000
	Constant	-1.386	.559	6.150	1	.013	.250

a. Variable(s) entered on step1: Strength Assessment
b. Variable(s) entered on step 2: Strength Leader
c. Stepwise procedure stopped because removing the least sig variable results in a previously fitted model

Because having a reported strength of *assessment* predicted *person who hoards at center of effort*, items that predicted a reported strength of *assessment* were also considered. A stepwise linear regression was used to eliminate criterion and identify possible predictors. At each step, a variable with the lowest criterion was removed. A reported strength of *person who hoards at center of effort*, *education*, *good leaders*, and *member expertise* predicted a reported strength of *assessment.*

As previously mentioned, 90% of participants reported a challenge in the area of *funding.* Thirty-nine percent of participants selected *Marketing and Public Relations* as a challenge, and *Volunteers* and *Communication* were selected as challenges by 33.3% and 36.4% of respondents respectively. Overall, there was a much higher level of consensus for funding as challenge as compared to other reported challenges from hoarding task force members across the United States. Of the nine participants who selected funding as a strength it is approaching significance to predict that they selected *secures funding* as a necessary skill for a good leader of a hoarding task force ($F = 3.325$, $df = 1$, $p = .051$), however the sample size was too small to consider it a reliable result.

A stepwise linear regression was used to eliminate criterion and identify possible predictors of a challenge with *person who hoards at center of effort*. At each step, a variable with the lowest criterion was removed (see Table 9). Reported challenges of *Community Outreach* and *Volunteers* predicted a challenge with *person who hoards at center of effort*.

Table 9

Predictors of Reported Challenge of Person who Hoards at Center of Effort

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1.317	1	1.317	9.724	.004b
	Residual	4.198	31	0.135		
	Total	5.515	32			
2	Regression	2.025	2	1.012	8.701	.001c
	Residual	3.49	30	0.116		
	Total	5.515	32			

a Dependent Variable: Challenge Person Who Hoards at Center of Effort
b. Predictors, Challenge Community Outreach, Volunteers

Research Question 3: How do members of hoarding task forces who feel their task force has good leadership perceive their relationship with other hoarding task force members in terms of working toward similar goals and availability for each other when problems arise as compared to those without strong, centralized leadership?

On a scale of four continuous choices, with one end being *not at all* and the other being *completely*, participants were asked if they had *similar goals and priorities* within their hoarding task force community. Thirty-three participants (100%) selected the choice closest to *completely* or *almost completely*. On the same scale, participants were asked whether members *of this hoarding task force community can count on each other* and if the task force community *has good leaders*. On these items, 31 participants (94%) indicated a choice of *completely* or chose the next closest option. Thirty participants (91%) indicated that they could *talk about problems.*

The means were as follows: *similar priorities* 3.48 (SD .508), *talk about problems* 3.52 (SD .667), and *count on each other* 3.33 (SD .595). A linear regression was used to identify possible predictors of having good leaders (see Table 10). *Meeting needs of people with severe hoarding difficulties in our community* was a significant predictor of also reporting having *good leaders*.

Table 10

Predictors of Good Leaders

		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.377	1	3.377	13.157	.001b
	Residual	7.956	31	0.257		
	Total	11.333	32			

a Dependent Variable: Good Leaders

b Predictors: (Constant), Meeting Needs

While ninety-one percent of respondents reported their hoarding task force *has good leaders* at a level of completely or almost completely on a four-point scale, only seven respondents (21%) selected *Leadership* as a strength of their hoarding task force. The two respondents who responded to having good leaders with "somewhat" or a rank of "2" still indicated *completely* or *almost completely* on having similar goals and priorities and *count on each other*.

Nine survey participants (27%) reported that they were the leader of the task force. Of those nine reported leaders, five receive compensation. The job titles for the five receiving compensation were Adult Protective Services Supervisor, Resident Service Coordinator and Housing Stability Specialist, Director of Hoarding Intervention and Treatment Program and In-Home Support Program, Forensic Manager, and a Resident Support Specialist who reported a portion of the participation was volunteer. Three of the volunteer leaders were Professional

Organizers with special training in hoarding or who was also a therapist. The fourth volunteer was a Program Manager in the field of Public Health.

Research Questions 4: What are the similarities and differences in operations (regularity of meetings, financial resources, and availability of education/training) for hoarding task forces throughout the United States?

Operations for the hoarding task forces represented in the study were similar on these issues. Ninety-four percent have regular meetings, 91% consider funding a challenge, and 85% offer opportunities for education and training. Consistency of regular meetings provides the necessary structure with which to problem solve and provide services for community members challenges with hoarding difficulties (Table 11). The task force members responding to this survey from throughout the United States have similar responses to these three items.

Table 11

Operations: Regular Meetings, Financial Resources, Availability of Education/Training

Operations	**Yes or Suspended Due to Pandemic**	**No**
Regularity of Meetings	31 (93.9%)	2 (6%)
Funding is a Challenge	30 (90.9%)	Not selected 3 (9%)
Education/Training	28 (84.8%)	5 (15.2%)

Research Question 5: According to hoarding task force members, what are the most effective leadership skills for hoarding task force leaders for managing hoarding task force operations?

The top reported skills for a good leader from a list of ten were: *Team-oriented, Identifies and Coordinates Resources, and Initiates Community Outreach, and Innovative Ideas* (Table 12).

Table 12

Skills Reported for a Good Hoarding Task Force Leader

Leadership Skill	N	%
Team-oriented	29	87.6
Resources	26	78.8
Innovative	25	75.8
Initiates Community Outreach	24	72.7
Detail-oriented	22	66.7
Balances Leadership Role with Other Tasks	20	60.6
Organizational Capacity	19	57.6
Enforce Policies	18	54.5
Funding	13	39.4

Research Question 6: What effect does the department/field of a hoarding task force member have on their beliefs about people living with hoarding difficulties?

On a scale of 1 to 9, participants were asked to rank their beliefs on the following questions: *How similar is a person with severe hoarding difficulties to the average person in United States?* (very similar = 1), *How respected is a person with severe hoarding difficulties to the average person in United States?* (very respected = 1), *How responsible is a person with severe hoarding difficulties for their condition?* (not responsible = 1). Participants reported their job titles and department or field (Refer to Appendix B for complete list). Departments were then coded into seven categories.

At this point in the results for ease of understanding, it was necessary to recode the results for the three items (see Table 13). Higher scores became positive, representing less stigma. *Difference:* mean for a person living with hoarding difficulties being *similar to* the average person in the United States was 4.45, with a higher score meaning very similar. *Disdain:* mean for a person living with hoarding difficulties being *respected* was 4.75, with a higher score

meaning closer to *very respected. Blame:* mean for how *responsible a person living with hoarding difficulties is for their condition* was 2.76, higher score closer to *not responsible*.

Table 13

Recode for Stigma: Difference, Disdain, and Blame

	Similar (Very similar = 9)*	Respected (Very respected = 9)	Responsible (Not responsible = 9)
Mean	4.45	4.76	2.76
N	33	33	33
St Dev	2.39	1.75	1.94

***Scale recoded 1-9 with 9 as high score**

A Cronbach's Alpha was used to measure the internal consistency of the three stigma items. The value of Cronbach's Alpha for the items was not close to .8, so the items could not be combined. The items continued to be measured separately (Table 14).

Table 14

Stigma Items Not Treated by Participants as the Same

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Similar	7.5152	6.758	0.163	0.053	-.017a
Respected	7.2121	10.672	0.003	0	0.359
Not Responsible	9.2121	9.547	0.172	0.053	0.021

a. The value is negative due to a negative average covariance among items.

Means were calculated by department / field and years on task force. The sample size for each category was too small to determine significance. The department/field believing a person with severe hoarding difficulties more similar to the average person in the United States was the Social Work / Mental Health / Therapist category **(5.72)** and those who have been a part of a hoarding task force for 11-20 years (6.2). Scores for whether a person with severe hoarding difficulties is respected were lower (not respected), with the highest trending mean reported by Relocation Specialists and Real Estate **(6.33)** and those who have been a part of a hoarding task

force for 6-10 years (5.5). The highest mean for scores for whether a person with severe hoarding difficulties is not responsible for their condition was reported by participants in the Professional Organizer category **(3.8)** and those who have been a part of a hoarding task force for 11-20 years (4.8). Higher stigma may result from less training and experience (see Tables 15 and 16).

Table 15

Participant Means for Difference, Disdain, and Blame by Department / Field

Dept/Field		Similar	Respected	Not Responsible
Adult Protective Serv.	Mean	3	4.6667	2.6667
	N	3	3	3
	SD	0	2.3094	1.52753
Enforcement	Mean	4.25	3.75	2
	N	4	4	4
	SD	2.62996	1.89297	0.8165
Prof Organizer	Mean	5	5.4	**3.8***
	N	5	5	5
	SD	2.34521	2.07364	2.68328
Prof Org w/	Mean	4	5	2
SW MH background	N	4	4	4
	SD	2.94392	2.94392	0.8165
SW / MH / Therapy	Mean	**5.7273***	4.2727	3.3636
	N	11	11	11
	SD	2.4532	1.79393	1.9633
Relocation /	Mean	3.6667	**6.3333***	2
Real Estate	N	3	3	3
	SD	1.52753	1.52753	1
Other	Mean	2	5	1.6667
	N	3	3	3
	SD	1	1	0.57735
Total	Mean	4.4545	4.7576	2.7576
	N	33	33	33
	SD	2.38604	1.93698	1.75054

* Stars show highest mean for each category by type of stigma.

Table 16

Participant Means for Difference, Disdain, and Blame by Years on Hoarding Task Force

Years HTF		Similar	Respected	Not Responsible
0-2 years	Mean	3.75	4.75	2.375
	N	8	8	8
	SD	2.18763	2.76457	1.30247
3-5 years	Mean	3.9167	4.5833	2.4167
	N	12	12	12
	SD	2.2747	1.44338	1.24011
6-10 years	Mean	4.875	**5.5***	2.375
	N	8	8	8
	SD	2.64237	1.92725	2.13391
11-20 years	Mean	**6.2***	4	**4.8***
	N	5	5	5
	SD	2.16795	1.58114	1.78885
Total	Mean	4.4545	4.7576	2.7576
	N	33	33	33
	SD	2.38604	1.93698	1.75054

* Stars show highest mean for each type of stigma.

Qualitative Thematic Analysis

Hoarding is a complex community health issue. Because perspectives of different stakeholders are involved with compulsive hoarding outcomes, this dissertation research study considered the people utilizing and receiving services in addition to the hoarding task force professionals. The quantitative portion of this mixed methods study of explanatory-sequential design studied the operational culture and viability (e.g., meeting needs, members involved for a long time, and hope for future) of hoarding task forces as a community response to hoarding. Interviews of participants meeting the selection criteria and responding to questions based upon analysis of the first phase were then conducted for this second, qualitative phase. Document analysis of hoarding task force websites was also performed to provide a more complete understanding of practices, policies, and operations and those results follow the interview results.

Hoarding task forces are often established to increase community awareness of hoarding, coordinate resources, potentially prevent homelessness, and improve community health. With this increased awareness and involvement of a variety of stakeholders, comes the opportunity for proactive implementation of mental health services to address co-occurring conditions. Previous research defined challenges with lack of insight for hoarding but did not consider the impact of readiness for change on the definition of successful outcomes (Frost, Tolin, & Maltby, 2010).

When hoarding task force members are not connected to people with hoarding challenges via first responders, they are often contacted by family members or neighbors who report the visible accumulation of stuff around the inside or outside of living spaces. The hoarding task forces may have a designated member, or outreach coordinator, to respond to the initial inquiry and direct the person to the appropriate department for their needs. The priority is assessing community safety risks.

Six themes that emerged from the analysis of the fifteen interview transcripts of the three groups (Hoarding Task Force Members, Family Members, People with Hoarding Challenges) included: (1) *Evolving, (2) Conflict, (3) Holistic Approaches, (4) Problem Solving, (5) Co-occurring Conditions, and (6) Readiness*. Quotes from the interviews are included with the description of each theme. These themes characterized the participants responses, and with insight from the survey responses, reached additional meaning.

A list of reported positive attributes of hoarding disorder and final thoughts from participants are included at the end of the qualitative results section, followed by the document analysis of 13 hoarding task force websites.

In addition to the six themes determined from the qualitative analysis, patterns for the overall tone of interviews surfaced:

- Hoarding task force member participants were **satisfied and proud** of their expertise and the work they were doing to raise awareness about the needs of people living with hoarding challenges in their communities. This passion was reflected in their responses.
- Family members sounded **frustrated, burdened, and protective**. They expressed concern about how to involve others while also protecting their family member from stigma and discomfort.
- The participants with lived experience were **curious and open-minded**. The tone of their responses demonstrated an intent to learn and make progress.

Research Question 7: What relationship do hoarding task force or other community interventions have on beliefs about hoarding from the perspective of members of hoarding task forces, people living with hoarding challenges, or family members of people living with hoarding challenges?

Beliefs about how best to address hoarding challenges have changed over the past twenty years. Initially, the focus was on the piles of belongings and how to keep responders and residents safe while clearing it out. Social workers and residential specialists then began to evolve their understanding of the mental health factors and started communicating with other departments. As televisions shows about hoarding gained popularity, awareness about hoarding in the community, along with misinformation and stigma increased.

Hoarding Task Force Member Perspectives for Theme 1: Evolving

According to the hoarding task force professionals, best practices for working with the complex community health issue of hoarding have evolved over time. As the hoarding task force

study participants learned more about the complexity of the disorder; they reportedly evolved their practices. They shared resources and started providing education and training.

Quotes from Hoarding Task Force Members exemplifying the theme of evolving:

"In the beginning, none of us knew any damn better." (HTF1)

"*When I first heard about the hoarding task force, I assumed we did cleanup*." (HTF3)

Hoarding Task Force Member Perspectives for Theme 2: Conflict

Participants reported that beliefs about how best to address hoarding are often accompanied by conflict. The involvement with hoarding task forces is not always voluntary, so members may be met with resistance. Because the stuff is just the visible tip of the iceberg, the path to a safe result depends upon the person's readiness for change. When hoarding task force members encounter resistance or refusals, several reported having built "*good cop/bad cop*" relationships with other community responders to minimize conflict while helping the person with hoarding challenges living in an unsafe manner.

Quotes from Hoarding Task Force Member exemplifying the theme of conflict:

"They want help from someone who understands their diagnosis, someone who has experience with helping. Someone who is not going to look down at them or treat them with any kind of stigma…I truly have to know the people who are going out there. If they're able to handle someone yelling, maybe saying they're going to die without their stuff." (HTF5)

Hoarding Task Force Member Perspectives for Theme 3: Holistic Approaches

According to several of the hoarding task force professionals, their approach to working with people with hoarding challenges has evolved into a holistic approach. They consider not just their clients' environmental health, but their mental, financial, physical, and social health. They reported educating others about holistic approaches to helping people with hoarding

challenges and recognize a responsibility to help others move past the conflicts around clean-outs and consider changing their thinking to wraparound services. Several participants indicated a belief that it is important to understand the "why" behind the hoarding to achieve sustainable results. Looking at hoarding as a way of coping reportedly takes the focus from the stuff to the person. Hoarding task force members also reported encouraging family members looking for a way to "*magically fix the problem*" to work on self-care, rather than focusing on the stuff.

Quotes from Hoarding Task Force Members exemplifying the holistic approaches theme:

"You have to get to what's underneath." (HTF4)

"*The assessment is not just assessing the house, but their health, finances, and social network... The case manager goes out and assesses and then the client is assigned. They have the case manager, a home therapist, and a home coach*. (HTF5)

"It turns out that folks who have hoarding disorder have trouble organizing lots of parts of their lives, not just the physical things." (HTF1)

Family Member Perspectives for Theme 1: Evolving

Family member participants reported an evolution of understanding and response strategies. Those raised in a hoarded environment adopted behaviors to keep themselves safe and have considered the impact of those traumatic events on their own mental health. Those who discovered their parent/s hoarding when returning home as adult children often felt responsible for remedying the situation themselves rather than expose their parents to outside scrutiny.

Quote from family member exemplifying the theme of evolving:

"I think the first time we were removed it must have been first or second grade. I always knew there was something, but I didn't know that anyone else had it. I

always thought it was my fault. I was told it was my fault. I didn't know it had a name or anything until the hoarding shows came out. It was just always something that was shameful and to be hidden." (F3)

Family Member Perspectives for Theme 2: Conflict

Family members shared experiences of a wide range of internal and external conflicts. They described the lengths they go to evade detection of the hoarding. One family member who is living with her parents shared she was having a *really bad week*, and another *struggles every day*, but believes the best result is to continue to let her mother with severe hoarding difficulties live with her. A third family member reported feeling conflicted about sharing the additional background about her grandparents and their hoarding. She wanted to state for the record that they were very lovely people

Quotes from family members exemplifying the theme of conflict:

"*I am pretty sure I could not get a professional to go upstairs at the moment. There is absolutely no way they (my parents) would allow that.*" (F5)

"In my parent's household, I definitely did do a lot of cleaning and I don't remember what age I was when I started just sneaking things out to throw away. Yeah, and I did a lot of that." (F1)

"And there are times when you just have to throw your hands up and be like, Okay, this week, things are just gonna be a mess because I just can't deal with it. I need a break." (F3)

"*I decided to find a therapist for myself. Because I realized it's hard to speak to my husband about it. It's just hard to do. I didn't want to be like he had a burden to fix my problems. Even though they are his in-laws and his frustration too you know?"* (F2)

Family Member Perspectives for Theme 3: Holistic Approaches

Family members were more likely to report overwhelm of the immediate problem of living in or feeling responsible for the piles of items, rather than encouraging reluctant family member with hoarding challenges to address their mental health issues. They did, however, have direct experience with mental, physical, social, and financial difficulties resulting from the hoarding behavior. Several family members reported seeking therapy for themselves but found therapists did not tend to have proper training to address the impact of hoarding on their lives.

Quotes from family members exemplifying the theme of holistic approaches:

"Living in an environment like that takes a toll on your physical health, your mental health, your social life. Your ability to function in your home is really diminished." (F1)

"There's comfort in the support groups that this behavior isn't as strange as I thought it was because it's very consistent with other people that are to this level and comforting me." (F4)

Perspectives for Participants with Lived Experience for Theme 1: Evolving

Participants with lived experience reported a curiosity and commitment to learning and connecting with others in their situation via the community, support groups, or social media. They shared their attempts to find strategies that work for their specific needs. Several reported ever-evolving attempts to one day achieve a comfortable living space where they feel comfortable having someone over.

Quotes from participants with lived experience exemplifying the theme of evolving:

"*We've had a decluttering zoom where a bunch of people who have hoarding disorder get together on my zoom, and we all declutter using the Pomodoro method. We'll do some modified Pomodoro...We do that for several hours and that's been really helpful."* (H1)

Participants with Lived Experience Perspectives for Theme 2: Conflict

A source of conflict reported by participants with hoarding challenges when seeking help was encountering well-meaning professionals not familiar with hoarding. Despite awareness of their challenges, people with hoarding challenges also described conflict with significant others in their lives because the decluttering pace was not proceeding as quickly as the partner would like. They shared about having encroached on previously cleared spaces causing the partner to react and respond.

Quotes from participants with lived experience exemplifying the theme of conflict:

"*They tried to get me set up with a case assistant through the county and that was kind of helpful. I had an in-home health nurse I was trying to see for other stuff, but she only wanted to declutter. That helped some, but it was really frustrating*." (H1)

"In the beginning of our marriage when he would try to get rid of things, especially toys, it would just trigger me like a fight or flight." (H4)

Participants with Lived Experience Perspectives for Theme 3: Holistic Approaches

People with hoarding challenges reported connections with previous life events or parents who hoard as catalysts for their own behavior. Several shared their preference for help that is not related to removing belongings, rather supporting them as an individual. They reported their challenges related to hoarding behaviors are about more than the items themselves.

Quotes from participants with lived experience exemplifying holistic approaches theme:

"*I think psycho education is hugely important. Because that can help with some of that shame and blame of self to understand that there's actually a physiological happening in each of us."* (H2)

"*My mom died when I was five. My dad died when I was 14. It seems to me buying things and having things is stability. Here I am. I'm not going to go away because I have this stuff."* (H5)

"The last time we tried to clean out the garage. I just started crying. I was hyperventilating crying." (H4)

The evolution of concentrating on the "stuff," to concentrating on the "why" for the person with hoarding challenges is on-going. This generation has the advantage of starting with societal awareness of hoarding the previous generation did not have. Family members are reportedly part of the equation, whether they are accommodating the behavior, dealing with unresolved trauma, or are frustrated trying to do something about it. Deconstructing the impacts, as well as the stigma and shame felt by family members will continue for the foreseeable future.

Research Question 8: How does the definition of a successful outcome for hoarding differ between hoarding task force members and people living with hoarding challenges or family members of people living with hoarding challenges who have been the recipient of community intervention for hoarding?

The definition of a successful outcome for hoarding is evolving. As mentioned in the previous Holistic Approaches theme, hoarding task force members report finding outcomes are different depending on the overriding diagnosis fueling the hoarding and the amount of safety risks. They recognize successful outcomes do not happen overnight and the internal progress can be difficult to see.

Hoarding Task Force Member Perspectives for Theme 4: Problem Solving

Hoarding task force members report coming together to problem solve issues members are having in their various agencies. Also mentioned was the issue of problem-solving funding

options leading to successful outcomes. They reported looking for ways to divert existing resources their direction. Expenses incurred for forced clean-outs, long-term support for the slower paced, holistic approach, court costs, and marketing and website maintenance all need solutions. Additionally, they shared needing immediate resources if housing is an issue.

Quotes from hoarding task force members exemplifying problem solving theme:

"With a tenant and a hoarding issue say there's an emergency to vacate in place. There's code enforcement involved, there may be someone from the health department. There're several individuals, teams, or our departments working together." (HTF2)

"What money is out there for housing preservation and eviction prevention? And how can we use those funds to help deal with hoarding issues?" (HTF1)

Hoarding Task Force Member Perspectives for Theme 5: Co-occurring Conditions

A repeated theme for all participants that impacted successful outcomes was, co-occurring conditions. Receiving therapy for mental health conditions such as anxiety, OCD, or ADHD, or being able to identify the impact underlying processing challenges such as autism, was described as essential for long-term success. As mentioned in the previous evolving theme, hoarding task force members reported their previous emphasis was on helping create a clutter-free environment, going so far as to pay for a storage unit, but have evolved to a more Holistic Approach that includes mental health supports.

Quotes from hoarding task force members exemplifying the theme of co-occurring Conditions:

"Those who come to us that have depression, they clean up and clear up quicker. Once that depression is lifted, their outcome, and outcomes ongoing look really good...Those who have more anxieties or OCD behaviors, we have to work

> *longer on retraining the brain and getting in new routines. It takes a long time to establish a new routine in someone's daily living."* (HTF5)

Hoarding Task Force Member Perspectives for Theme 6: Readiness

Hoarding task force members reported evolving their thinking to learn what stage of readiness a person with hoarding challenges a client was operating from before deciding on an appropriate plan for services. They explained that a lack of readiness impacts outcomes because backsliding or resistance can occur. Recognizing this readiness during the assessment process gave them a better success rating with clients.

Quotes from hoarding task force members exemplifying the theme of readiness

"There are some people who just refuse, and some end up evicted and lose their housing. But we really try to prevent that from happening." (HTF1)

> *"Several times we've been able to get the unit clean to the to where they stay and we know that maybe a couple of months or maybe even longer, they will have brought the issue back to the forefront because they're introduced a lot of things back into their environment."* (HTF2)

Family Member Perspectives for Theme 4: Problem Solving

Several family member participants described finding confidential guidance and support via social media platforms, rather than hoarding task force websites. This medium proved useful for framing expectations and locating resources when involving outside agencies was not desired. Problem solving solutions to conflicts was disclosed as a daily struggle for some family members.

Quotes from family members exemplifying problem solving theme:

"(IOCDF website) They have a section specifically on hoarding, but I find it difficult to navigate to dig and dig again. Not everything's current." (F2)

Family Member Perspectives for Theme 5: Co-occurring Conditions

Family members who did not report having hoarding challenges themselves, often had other processing or emotional issues that might impact work toward successful outcomes. Two participants noted they had a child experiencing developmental delays consistent with autism. Another adult child who participated as a family member reported having autism which left her *85% independent* and not as able to leave the hoarding in the family home to live on her own.

Family Member Perspectives for Theme 6: Readiness

What does lack of readiness for change look like for a person with hoarding challenges? One family member described it like this, "*If I find a bag of walnuts from 1999, I know my parents would really be like, 'Oh, well, nuts don't go bad if they're in the freezer.*'" (F1) A family member may also experience a lack of readiness accepting the hoarding habits of their parent/s. One participant attempted to read a recommend book suggestion from her therapist, "*It's so hard to read the content. I read a couple pages. It is stressful for me."* (F2) Family members report frustration at the impenetrable nature of lack of readiness. One participant reported she is careful not to use the word hoarding, or the family members *defenses go way up*.

Quotes from family members exemplifying readiness theme:

"We found out all of his food was being stored outside in his Recycle Bin. He had a microwave plugged in outside when the tree fell knocking out all the power...So now he had no plumbing, no water, no power." (F4)

People with Lived Experience Perspectives for Theme 4: Problem Solving

A participant with hoarding challenges reported they were seeking change for their environment because of the addition of a service dog. They were working to accommodate this new resource without pushing themselves too fast. For this participant, problem-solving how to incorporate a safe environment for the dog was a priority. One participant with hoarding challenges expressed a desire to be able to afford professional organizing services. All participants described problem solving to achieve resource and funding solutions.

People with Lived Experience Perspectives for Theme 5: Co-occurring Conditions

While all participants reported co-occurring conditions that impact successful outcomes, they were not limited to mental health issues. One participant with hoarding challenges reported co-occurring health issues of chronic migraines and a sleep disorder. General health problems reportedly may cause hoarding task members to consider hospitalization for their clients.

Quotes from people with lived experience exemplifying co-occurring conditions theme:

"I have ADD, which I struggle with…Being on TikTok and hearing all the stories of people opened up my understanding of ADD. I've never heard of so many people with the same issues as me." (H3)

"I was seeing a counselor for other things. And I happen to mention to her that I had a shopping addiction." (H5)

"I've realized I have a really short attention span, which actually works in my favor because if I'm experiencing extreme distress about getting rid of something, it's going to be over pretty soon I'm going to forget and move on to something else." (H1)

"The therapists, they're trying to do exposure therapy. It just makes it worse...I tried to explain it if you told me, hey, you just have to drown this puppy and the more puppies you drown you just get used to it. That to me what exposure therapy is." (H2)

"I do have arthritis, heart issues. Mentally, I'm beginning to think I'm depressed." (H5)

People with Lived Experiences Perspectives for Theme 6: Readiness

People with hoarding challenges report seeking education, followed by seeking support from their hoarding peers. One participant explained how she brought her father with hoarding challenges to support groups, but it took several sessions before he made connections to his own behavior. Being able to connect with others who were also working on hoarding challenges was a reported benefit for participants with hoarding disorder as they became more open to change.

Quotes from people with lived experience exemplifying readiness theme:

"Every so often there's a shift, and suddenly things get way easier." (H1)

"Maybe when you're feeling calm and safe and open to and realizing that you don't need this to protect yourself anymore or to maintain safety. Or connection or whatever." (H2)

"I'm like, Oh my gosh, there's an LGBT one. And so, I signed up for that one immediately. And that's how I got involved. I got a clutter coach off that and then I'm on to CBT for hoarding now." (H1)

Positive Attributes

The final question for each interview, before offering participants an opportunity to share anything else they felt pertinent, was, "What are some positive attributes of hoarding disorder?" Most participants took a long pause. Two of the family members quickly offered, "*I can't think of anything,*" or "*I can't think of anything positive"* but each participant went on to contribute opinions. A list of the responses is as follows:

"Really giving people" (Altruism/generosity)

"Ability to see the beauty in things"

"Mechanism for coping"

"Very creative people"

"Ability to hyperfocus"

"*They want to be prepared*"

"Sentimental"

"They are the smartest people I know"

"Valuing family pictures and mementos"

"*Problem solvers"*

"We got to eat out at restaurants"

"Good at tinkering with stuff and fixing things"

"I always have what people need in my purse"

A common response following the offer for participants to share additional insight was that increased mental health issues due to the pandemic will cause rates of hoarding to rise, "*The numbers are going to double. Easy.*" (HTF5) and "It is m*ore prevalent than it looks.*" (F2)

Document Analysis

For the purposes of using multiple data sources, phase two of this research study included document analysis of 13 hoarding task force websites. The websites represented hoarding task forces in AZ, CO, CT, FL, GA, IL1, IL2, KS, ME, MD, MASS, MI, and MT. A spreadsheet was used to gather information in a yes/no format. Criteria were as follows:

Website Analysis

1. *Information is current, links are active, etc.*
2. *Stated Purpose / Mission Statement*

3. *Calendar of Meetings*
4. *Calendar of Trainings/Educational events*
5. *FAQs*
6. *Point of contact (outreach coordinator)*
7. *Departments of Task Force members*
8. *Contact information: email, phone, etc.*
9. *Links to information about hoarding*
10. *Other resources*
11. *Website separate from county website (stand-alone website)*
12. *Website content contains success-oriented and supportive terms*

Eleven of the 13 websites (84.62%) listed their mission and had active links on the site. Ten of the sites (76.92%) had current information and appeared to be actively monitored. Three of the websites (23%) showed an up-to-date calendar of events and two (15.38%) used success-oriented and supportive terms. The scores ranged from 12/12 (100% contained all 12 criteria) to 1/12 (8% contained one item of criteria). The mean was 6.69 (56%). Example of success-oriented and supportive terms from a website meeting 12/12 criteria:

Task Force Core Values

- *Respect the Individual*
- *People who hoard are often experiencing multiple issues which frequently requires the assistance of others to manage and recover.*
- *Reasons for the behavior can be difficult to identify, may be varied, and multidimensional*
- *Each individual who hoards requires compassion, individualized assessment and services*
- *People who hoard deserve courtesy and respect*

Discussion

Experts report that hoarding affects 19 million adults, or 2-5% of the population, but this does not include children, family, neighbors, or the community (Buscher et al., 2013; Minor and Youth Children of Hoarding Parents, 2021). Unfortunately, people living with severe hoarding challenges often place blame on external factors and resist intervention (Matthews, 2014). People who hoard may also keep conditions a secret—out of fear of remediation, societal stigma, or having awareness at the pre-contemplation stage of readiness for change. When seeking support, it is usually not for hoarding but for a co-occurring condition. A first responder, neighbor, or adult protective services professional may be the first to report the living conditions and there is not a clear path for remediation.

Traditional types of interventions for people with hoarding challenges are treatments such as Cognitive-behavioral therapy (CBT) or the *Harm Reduction* approach (Tompkins, 2011). CBT is most helpful for desensitizing the emotional triggers around releasing items but does not address underlying reasons for the behavior (Landau, 2011). Chou, et al., 2020, acknowledged CBT as the current standard, but found some effects limited and examined the use of Compassion-Focused Therapy (CFT) as a follow-up. The *Harm Reduction* approach is usually implemented with a family member or paid professional. The training utilizes a specific interview technique that requires patience and training (Carpenter et al., 2014). This may not be realistic for the dynamic of families challenged by years of enduring hoarding behaviors. *Buried in Treasures Workshops* are an opportunity for a person living with hoarding disorder to gather with others for encouragement and to gain understanding of their behaviors (Frost et al., 2012). Based upon the *Buried in Treasures Workbook*, these support group style workshops provide a

supportive environment for people to challenge and change their habits. The workshops are highly structured and short-term (Tolin et al., 2014).

Many perspectives come into play with compulsive hoarding. There is the perspective of the person who hoards, their family, community members, therapists, and community responders enforcing safety needs, among others. Because hoarding is a complex community health issue, this dissertation research study evaluated the factors that impact the operational culture of hoarding task forces pertaining to current practices, leadership, psychological sense of community between members, and stigma around hoarding, generalizing the findings of a Bratiotis (2012) qualitative study of five hoarding task forces. Operational culture and viability (e.g., meeting needs, members involved for a long time, and hope for future) of hoarding task forces as a community response to hoarding with a larger representative sample was considered. Semi-structured interviews of hoarding task force members, family members, and people living with hoarding challenges were utilized to learn more about the relationship between hoarding task force members and approaches to services, expectations, treatments for hoarding, and redefining pathways for success. Document analysis of hoarding task force websites was also conducted to provide a more complete understanding of community outreach and resources.

Items from Chasson et al. (2018) were used to consider levels and types of stigma (difference, disdain, and blame) held by members of hoarding task forces and experienced by family members and people living with hoarding challenges. Previous research identified insight-related challenges but had not considered the impact of readiness for change on the definition of successful outcomes (Frost, Tolin, & Maltby, 2010). The Transtheoretical Model of Change runs contrary to the idea popularized by the hoarding television shows that imply lifestyle changes for a person living with hoarding challenges begin with a quick clean-out. Interview questions

exploring successful outcomes for people living with hoarding challenges were included to better understand how community responders can meet the needs of people with hoarding challenges in their community.

Key Findings

1. **Hoarding task force viability (e.g., meeting needs, members involved for a long time, and hope for future) increases by first establishing standard practices such as: identifying a stated purpose, holding regular meetings, and offering education and training opportunities**. **Within this structure, members of hoarding task forces who expect to be a part of the task force for the long-term evolve and share their approaches allowing them to feel hopeful about the future.** Considering co-occurring conditions and being open to creative problem-solving are also suggested as part of a more long-term holistic, or wraparound, approach. Keeping websites current and utilizing success-oriented language can also help with community outreach and engagement for the long term.

2. When considering strengths and challenges, the similarities in strengths for hoarding task forces across the United States are referral networks and/or resources and offering education and training opportunities. Having good leaders and an initial assessment as reported strengths predicted having the person who hoards at the center of the effort. Most hoarding task force members reported challenges with funding. Those who reported funding as a strength also believe a quality in a successful hoarding task force leader is the ability to secure funding.

Most members who took part in the study think their task force has good leaders, but only a quarter of participants selected leadership as a strength of their task force. The most effective leadership skills deemed necessary for successful hoarding task force leaders were being team-

oriented and able to identify and coordinate resources. Selected slightly less often were having innovative ideas and initiating community outreach

3. When considering the effect of department/field of a hoarding task force member on their beliefs about people living with hoarding difficulties, the trend shows that those with specialized training and/or direct experience responded with less stigma in the categories of *difference, disdain*, and *blame* when compared to the average person in the United States. Of particular note were hoarding task force members who have been a part of the task force for over 11 years. These long-term members did not believe as strongly as their hoarding task force peers that people with severe hoarding challenges are less respected.

4. All three groups (members of hoarding task forces, family members of people living with hoarding challenges, and people living with hoarding challenges) consistently commented on and expressed similar views regarding beliefs about hoarding resulting in the following three themes: *(1) Evolving, (2) Conflict, and (3) Holistic Approach.*

1. Best practices for working with the complex community health issue of hoarding **evolve** with direct hands-on expertise and experience.

2. **Conflict** is to be expected and stakeholders should recognize and consider the potential for proactive approaches.

3. The trend for successful outcomes with hoarding challenges is for hoarding task force members to work towards a **holistic approach**.

All three groups (members of hoarding task forces, family members of people living with hoarding challenges, and people living with hoarding challenges) consistently commented on and expressed similar views regarding successful outcomes for hoarding in three areas: *(4) Problem Solving, (5) Co-occurring conditions, (6) Readiness.*

1. Successful outcomes for hoarding involve creative **problem solving** and out-of-the box thinking for resource and funding solutions.

2. Treatment for **co-occurring conditions** contributes to overall improvements in mental health allowing the person who hoards be more available for change.

3. Tailoring approaches to consider stages of **readiness** for change for the person living with hoarding challenges is critical for successful outcomes.

Does having established practices and policies for a hoarding task force impact the viability (e.g., meeting needs, members involved for a long time, and hope for future) of the hoarding task force for the long term?

The data suggest that hoarding task forces should expect to have a stated purpose, regular meetings and offer education and training. The results of the survey of hoarding task force members indicated that most of the participants were part of a hoarding task force that has a stated purpose and holds regular meetings. Because of this high percentage, it is not clear if these practices and policies have a direct impact on viability but should be considered standard practice. Opportunities for training and education programs should also be provided.

It should be noted that the first round of data was collected during a global pandemic when many areas of the United States were not open for in-person meetings. It would be interesting to know if all the programs resumed regular meetings and, if so, how many took advantage of on-line options and moved meetings to a virtual platform. One interview participant indicated their meetings had not yet resumed.

Most members of a hoarding task force with a stated purpose, regular meetings and opportunities for training and education indicated their hoarding task force members have similar priorities and goals. They also expect to be a part of their hoarding task force community for a

long time and feel hopeful about the future of their hoarding task force community. Laying the groundwork for this psychological sense of community for a hoarding task force most likely begins with the dependable structure of having a stated purpose, a commitment to hold regular meetings, and potential for education and training.

While most members felt hopeful about and committed to their task force, less than half reported feeling successful about meeting needs of people living with severe hoarding difficulties in their community. This is consistent with research demonstrating there is not a clear path to remediation for hoarding. These professionals were, however, committed to working with other members of their hoarding task force community to manage the problems and felt hopeful about the future. Interview participants emphasized the importance of evolving current approaches to a more holistic, wraparound program that includes long terms maintenance.

When Bratiotis (2012) compared how hoarding task forces are organized, she noted they were often grassroots efforts and that having a front-line professional in a leadership role did not guarantee success for the long term. Her results from five case studies suggested that structural factors impact viability. The data from this current study supported and generalized the findings that viability is more dependent upon having a stated purpose with regular meetings and opportunities for education, rather than having a single front-line professional in a leadership role. With this consistency and structure, establishing similar priorities and goals and opportunities to work towards a sense of community are also helpful. Establishing a website that highlights these structures provides opportunities for community connection.

What are the similarities and differences in reported strengths and challenges for hoarding task forces throughout the United States?

Study participants from across the United States were asked to select strengths and challenges of their hoarding task forces from provided lists. The lists were based upon the reported sub themes from a 2012 study of hoarding task forces (Bratiotis, 2012). Those study findings suggested leadership, purpose, funding, and membership impact hoarding task force viability. The current study supported and generalized the findings with fifty-four percent or more of participants reporting strengths in the areas of *Referral networks and resources, Education and training opportunities, Communication, and Member Expertise.* With a majority of respondents reporting a challenge for *funding sources for hoarding task force services* as a challenge, it is not clear how this impacted viability. Funding was not often listed as necessary quality for a leader and hoarding task force members feel hopeful about the future and committed to the hoarding task force, despite the struggles with funding. Interview participants suggested problem solving ways to divert funds from existing financial sources such as housing and eviction. An additional problem with reporting funding as a challenge is a lack of attention to updating and maintaining a hoarding task force website which can be an effective tool for communication, sharing resources, and marketing and public relations.

How do members of hoarding task forces who feel their task force has good leadership perceive their relationship with other hoarding task force members in terms of working toward similar goals and availability for each other when problems arise?

Effective leadership of a nonprofit can promote learning and capacity for change, as seen in previous research on organization cultures (Balser & McClusky, 2005). While ninety-one percent of respondents reported their hoarding task force *has good leaders* at a level of

completely or almost completely, only twenty-one percent selected *Leadership* as a strength of their hoarding task force. While the leaders were reportedly good, they were not an overall reported strength, which supports the Bratiotis 2012 result that leaders are not a guarantee of success. It appears that task force members place a higher value on referral networks and resources to implement goals rather than effective leadership.

Sense of Community items, *having similar priorities for the hoarding task force* and *talking about problems* was not significantly related to reporting *having good leaders*. *However, having good leaders* significantly correlated with *meeting the needs of people with severe hoarding challenges in our community*. This data could suggest that having good leaders is effective for meeting needs. Further research is needed because the small sample size of this study impedes the ability to generalize the results. It should also be noted that having a challenge with *having good leaders*, significantly correlated to having a challenge with providing *education and training opportunities.*

What are the similarities and differences in operations (regularity of meetings, financial resources, and availability of education/training) for hoarding task forces throughout the United States?

Operations for hoarding task forces represented in the study were similar: most have regular meetings, consider funding a challenge, and slightly less often offer opportunities for education and training. The biggest difference was whether they continued with regular meetings or if they were temporarily suspended due to the pandemic. Consistency of regular meetings provides the necessary structure with which to problem solve and provide services for community members challenged with hoarding difficulties.

Participants were asked whether they volunteer their time and expertise, receive a stipend, or if the services provided are compensated as part of their regular job description. The split revealed slightly more volunteerism. This difference is interesting compared to the consistency of the other responses, suggesting compensation of members does not affect hoarding task force viability, types of strengths and weaknesses, or sense of community.

According to hoarding task force members, what are the most effective leadership skills for hoarding task force leaders for managing operations?

The top reported skills from a list of ten skills needed for a successful hoarding task force leader was that the leader be *Team-oriented, Identify and Coordinate Resources, Initiates Community Outreach,* and have *Innovative Ideas.* Whether it applied to self-designated leaders or appointed leaders did not yield significant results. Previous research of the operational culture of task forces showed that effective leadership for nonprofits have a consistent rationale for decision-making (Balser & McClusky, 2005). Because most hoarding task forces reportedly have good leaders and hold regular meetings, this offers opportunity for leaders to include consistency with decision-making.

What effect does the department/field of a hoarding task force member have on their beliefs about people living with hoarding difficulties?

While the sample size for each category was too small to determine significance, the department or field for believing that a person with severe hoarding difficulties is more **similar to** (measure of difference) the average person in the United States was the Social Work/Mental Health/Therapist category. This is lower than the average mean found for participants of the Chasson (2018) study, 591 adults who completed the on-line measure, meaning it was closer to thinking they are *very similar*.

The score for whether a person with severe hoarding difficulties being **respected** (measure of *disdain*) with the lowest trending mean were those who have been a part of a hoarding task force for 11-20 years. This is lower than the average mean found for participants of the Chasson (2018) study, meaning it was closer to *very respected*.

The lowest mean for scores for whether a person with severe hoarding difficulties is **responsible** (measure of *blame*) for their condition was reported by participants in the Real Estate/Residential/Relocation category. This is lower than the average mean found for participants of the Chasson 2018 study, meaning closer to *very responsible* (1/9).

The data indicates that those with specialized training respond with less stigma in all categories, *difference, disdain,* and *blame,* about people living with severe hoarding challenges because the means were lower than participants of the Chasson (2018) study and the three participants in the *Other* category from this study. It was, however, not clear whether participants in the *Other* category had specialized training, the size of the current study is small, and the ranking of the questions could be confusing.

What relationship do hoarding task force or other community interventions have on beliefs about hoarding from the perspective of members of hoarding task forces, people living with hoarding challenges, or family members of people living with hoarding challenges?

Beliefs about how best to address hoarding challenges have evolved over the past twenty years. Initially, the focus was on the stuff and how to keep responders and residents safe while clearing it out. Social workers and residential specialists began to understand the mental health factors and started communicating with other departments to reduce conflicts and teach about holistic approaches. As televisions shows about hoarding gained popularity, awareness in the community increased, as did an increase in stigma and an expectation for rapid results. Several

hoarding task force member interview participants recognized a responsibility to help other professionals move past the conflicts around clean-outs and consider changing their thinking to wraparound services and incremental habit change.

"*The assessment is not just assessing the house, but their health, finances, and social network... The case manager goes out and assesses and then the client is assigned. They have the case manager, a home therapist, and a home coach*. (HTF5)

In part because of the media, this generation is starting with an awareness of hoarding the previous generation did not have. Family members (some who were raised in a hoarded environment) evolved strategies to keep themselves safe and/or chose to maintain secrecy around the family member with hoarding challenges to reduce conflict. They may still believe they are responsible for remedying the situation themselves rather than expecting a reluctant family member to be open to community assistance. They may recognize hoarding or other co-occurring conditions in themselves and would benefit from consideration of holistic approaches. Some may not be at a stage of readiness to "see" beyond what they feel is their responsibility. This adult child who was removed from the home as a child due to unsafe conditions believed she was somehow responsible for her mother's behavior until watching the tv shows about hoarding.

"I think the first time we were removed it must have been first or second grade. I always knew there was something, but I didn't know that anyone else had it. I always thought it was my fault. I was told it was my fault. I didn't know it had a name or anything until the hoarding shows came out. It was just always something that was shameful and to be hidden." (F3)

People with lived experience report a curiosity and commitment to learning and connecting with others in their situation via the community, support groups, or social media. Those who have evolved towards readiness to change often avoid conflict by continuing to keep

their living conditions hidden. They benefit from holistic approaches to healing and would like to believe they can eventually achieve a comfortable living space that allows them to socialize with others. Using the word, "comfortable" to describe a living space is an important distinction for defining success, rather than striving for the environment to be clean and organized.

The participant with hoarding challenges quoted below had reached determination stage of change but had not yet been successful in certain areas of the stage of action. She reported her husband was being patient and supportive to keep her from backsliding.

"In the beginning of our marriage when he would try to get rid of things, especially toys, it would just it would trigger me like a fight or flight." (H4)

How does the definition of a successful outcome for hoarding differ between hoarding task force members and people living with hoarding challenges or family members of people living with hoarding challenges who have been the recipient of community intervention for hoarding?

Hoarding task force members reported definitions of successful outcomes are different depending on the overriding diagnosis fueling the hoarding and the amount of safety risks. They recognize internal progress with co-occurring conditions and moving along the cycle to readiness for change can be difficult to see because of the existing piles. They report coming together to problem solve issues members are having in their various agencies and recognize successful outcomes do not have to mean "neat and tidy" according to societal standards, but rather incremental changes in awareness.

"Those who come to us that have depression, they clean up and clear up quicker. Once that depression is lifted, their outcome, and outcomes ongoing look really good...Those who have more anxieties or OCD behaviors, we have to work longer

on retraining the brain and getting in new routines. It takes a long time to establish a new routine in someone's daily living." (HTF5)

While **family members** also reported problem-solving solutions, this was more often disclosed as a daily struggle rather than as a success. Expenses incurred for decluttering, long-term support, treating co-occurring conditions, and court costs all need solutions. Lack of readiness for change is a pervasive issue for problem solving what do about living conditions for the hoarding, but family members are also moving through their own stages of grief and acceptance. Family members were more likely to define a successful outcome as a yet unknown future time the home is finally cleared out.

"There's comfort in the support groups that this behavior isn't as strange as I thought it was because it's very consistent with other people that are to this level and comforting me." (F4)

People with hoarding challenges desire support from their hoarding peers as they move along the cycle of readiness for change. This aligns the Transtheoretical Model of Change theory because a person living with hoarding challenges cannot skip stages to a manageable life. The structured approach and positive habit changes of the model align with shift in insight needed for people living with hoarding behaviors to change through a process that recognizes their needs (Prochaska & DiClemente, 1982). This recognition is the beginning of the opportunity for a successful outcome.

Every so often there's a shift, and suddenly things get way easier. (H1)

Limitations

Those who chose to participate in the research may have been personally invested in the success of their hoarding task force and responded accordingly. In addition, the small sample size meant it was not a random sample of all hoarding task force members and was too small to

generalize the results. This also increased the possibility of a type II error, confirming the hypotheses when they are not true.

The challenge finding of participants mirrored issues the general public may have finding help for hoarding in their area. Throughout the United States, an internet search often turned up a paid franchise service for hoarding before a locally funded resource. Twenty percent of states had no on-line public resources listed. One participant shared an effort underway to create a national listing of hoarding task forces, which she acknowledged could be challenging to keep up to date. See Appendix B for a shareable national listing created and used for this study.

Another limitation may have been using the SCI-2 item, *based upon your experience, this Hoarding Task Force has been successful in meeting the needs of people living with severe hoarding difficulties in your community*. Few respondents reported being completely successful in meeting needs. This raised a question about different definitions of success for people living with hoarding challenges and whether participants considered different definitions when responding to the item. It would be interesting to know if members who reported being successful meeting needs hold the belief that a reluctant person with hoarding disorder could be considered successful if they move into the next stage of readiness and begin to contemplate learning more about hoarding, home safety, or other co-occurring conditions, as opposed to living clutter-free.

Lessons Learned and Implications for the Future

The results of this Pilot Research Study confirmed the Bratiotis (2012) findings that hoarding task forces benefit from having a stated purpose, hosting regular meetings, and providing education and training. Having a team-oriented leader who identifies, and coordinates resources is also reported as important. Because turnover is a constant, relying on one person to

hold the task force together can be problematic if that person retires, changes departments, or otherwise transitions away from the role. Establishing a sense of community can contribute to the viability of a hoarding task force, defined as having members committed for the long-term who are meeting needs and feel hopeful about the future. Additional case studies that focus on types of assessments currently in use by these departments and fields would yield helpful information for hoarding task force members.

As members work together in their communities, best practices continue to evolve, and we learn what types of interventions are most successful. The trend indicates that a holistic, or wraparound, approach considering co-occurring conditions and readiness for change is perceived as effective. A sense of community can mediate the psychological distress of mental illness, so future research considering the efficacy of peer support groups for people living with hoarding challenges would also be beneficial (Terry, et al., 2019).

Consistent with previous research on non-profits, providing education and training have been shown to raise awareness and reduce stigma, so hoarding task forces members that provide education and training can potentially reduce stigma around hoarding in their communities. Approaches for helping a person who hoards and/or their families should involve reducing stigma, secrecy, and shame and consider a holistic approach rather than concentrating on the visible mess (Orr et al., 2019). At the community level, it is helpful to focus on the issue from several perspectives because stigma can also be present with community responders and mental health professionals (Bratiotis, 2012).

Establishing a county-wide hoarding task force is an effective way to bring stakeholders together to problem solve hoarding situations in the local community and offer opportunities for education and training. The result is task force members who look beyond “crisis mode clean-

outs" and coordinate approaches (Bratiotis, 2012). Findings also suggested that offering a full range of services is necessary. It is important for mental health practitioners to be included so they can monitor a person living with hoarding difficulties to proactively mitigate resultant issues.

Funding challenges are numerous and deserve attention. In addition to a lack of access to services and resources, lack of attention to updating and maintaining a hoarding task force website can also be affected. A website is an effective tool for communication, sharing resources, and marketing educational events.

People who hoard and/or their families may not feel similar to others and keep their living conditions a secret to avoid stigmatization. It is important for professionals supporting these individuals to establish a sense of community within their own mission-driven team. Hoarding Task Forces are an opportunity to create these connections with a variety of community responders and extend into the community which can lead to better outcomes for the people they serve.

Conclusion

It is critical to recognize hoarding as a complex community health issue. While a decade of reality television shows has heightened awareness of hoarding challenges, it has potentially exacerbated stigma and misconceptions and raised expectations for a rapid result (Chasson et al., 2018). As previously mentioned, experts report that hoarding affects 19 million adults, or 2-5% of the population (Buscher et al., 2013). Several interview participants in this study predicted the number will continue to rise due to an increase in mental health issues emerging from living through a global pandemic.

Hoarding Task Forces enter the equation as a multidisciplinary community approach to compulsive hoarding. Viable hoarding task forces have a stated purpose, hold regular meetings, and provide education and trainings that help communities move beyond crisis-driven responses, increasing the potential for more successful outcomes. Strong referral networks, communication between departments, and member expertise that evolves with new research results in communities that are better equipped to reduce stigma and mitigate health and safety issues that arise. Having a coordinated response helps influence policy and resource allocation.

Eliminating excess is overwhelming for people who hoard. Their challenges are often compounded by co-occurring conditions and not having reached an actionable stage of change. For example, a person with hoarding difficulties may reach a stage of readiness where they acknowledge they should get rid of things but may not be ready to take steps to begin the process. Strengths such as seeing the beauty in objects, creative problem solving, and the ability to hyper-focus rarely enter the conversation but should be considered. One participant with "lived experience" reported a strength of her hoarding challenges as, "*I always have what people need in my purse!*"

The evolution of concentrating on the "stuff," to concentrating on the "why" for the person with hoarding challenges is on-going. Hoarding task forces that shift to a more holistic approach, engage in creative problem solving, acknowledge support may be needed for family members conditioned to use appeasement strategies to reduce conflict, consider co-occurring conditions, and determine readiness for change are better prepared to help with hoarding in their communities. While some cases require immediate intervention for mitigating safety, shifting the emphasis from rapid clean-outs to coordinated wraparound services is recommended.

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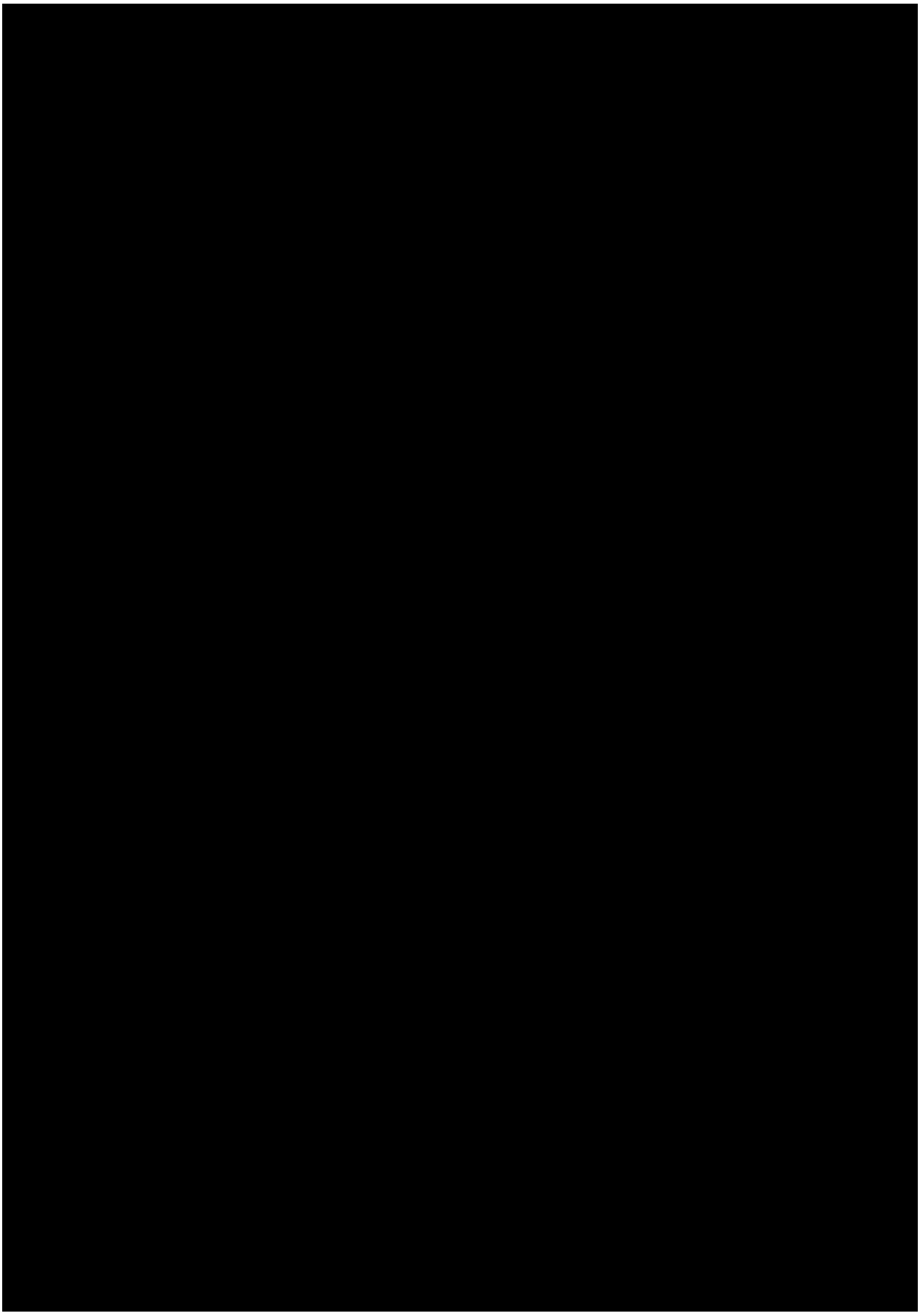
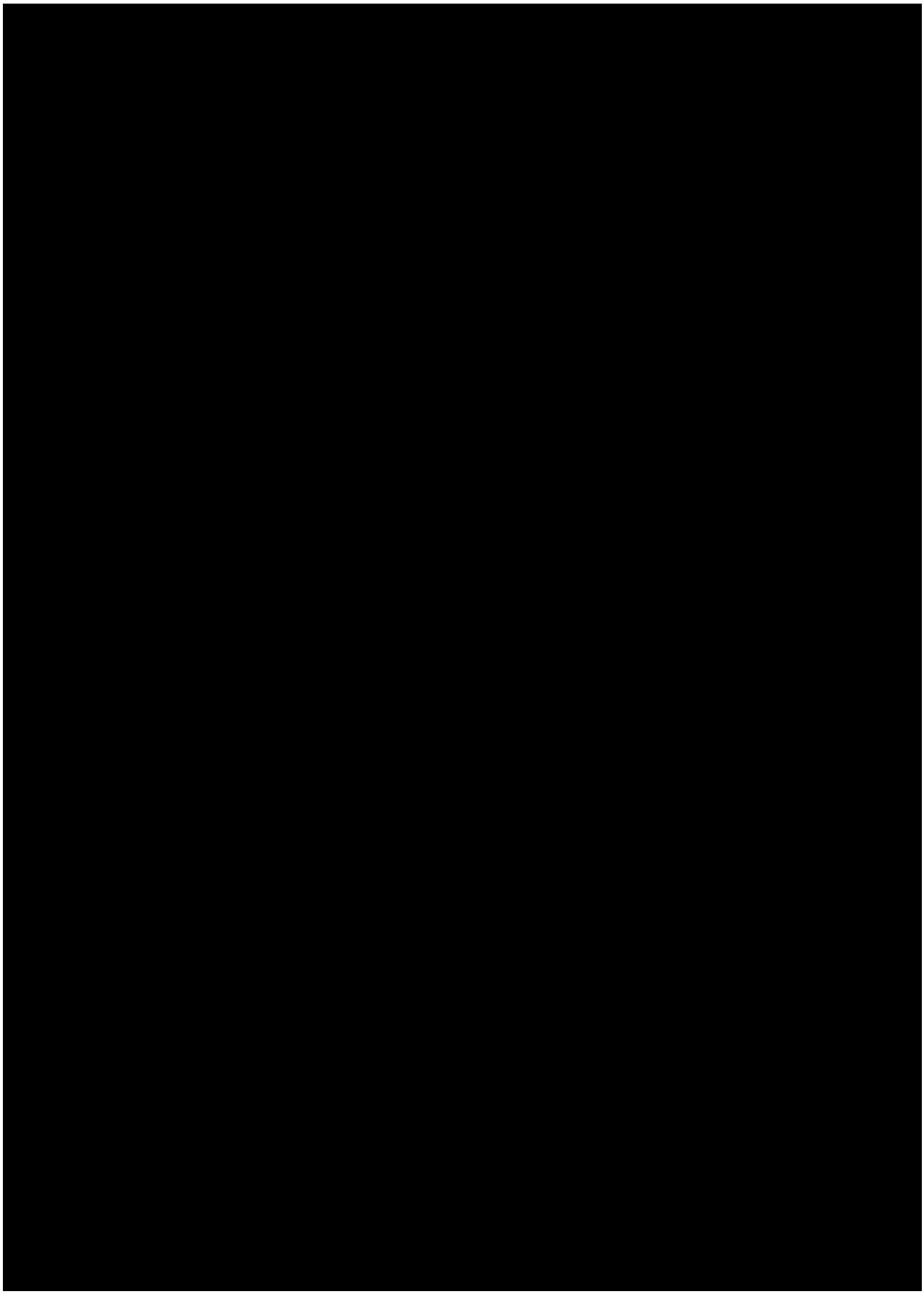
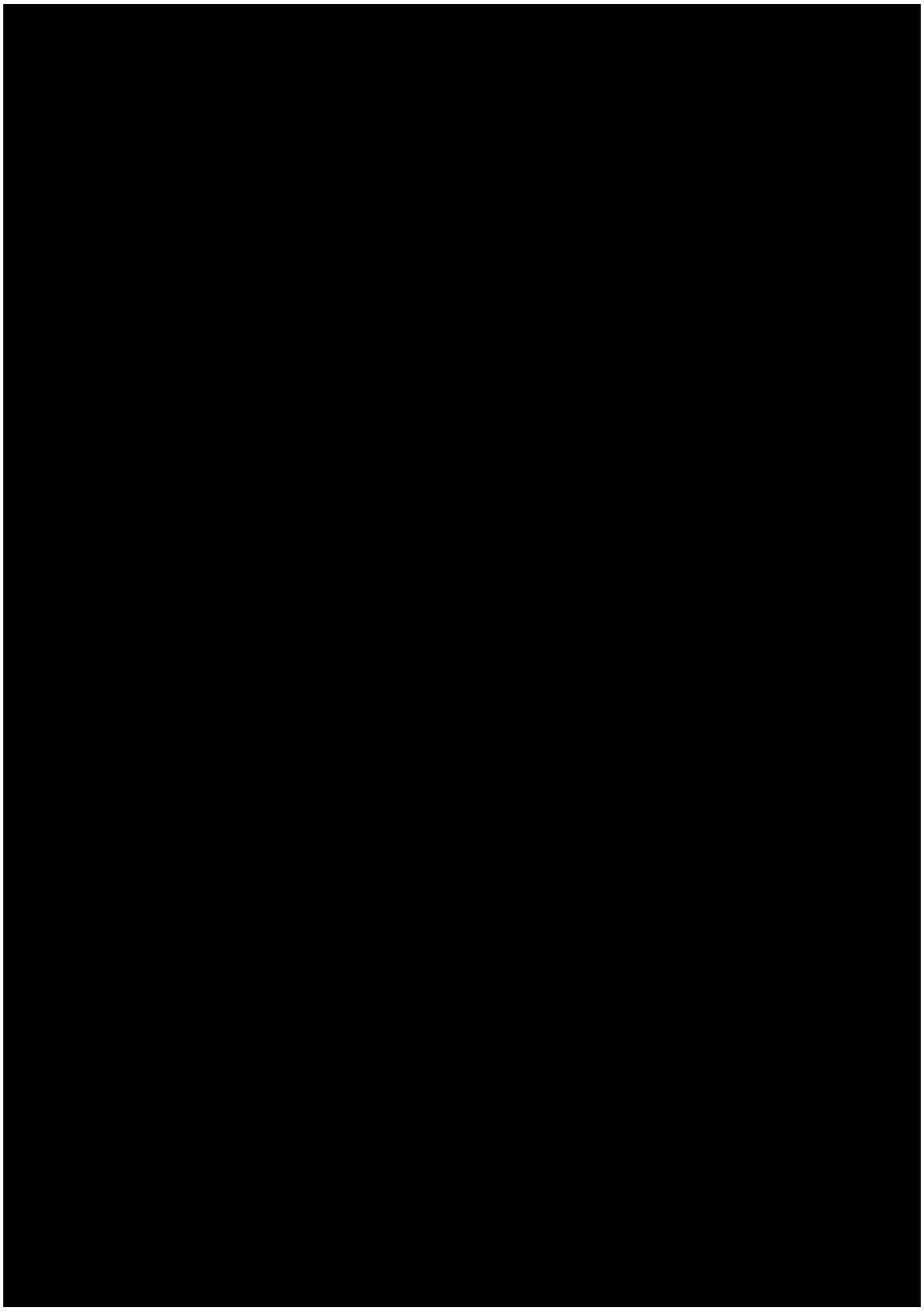
Appendix A

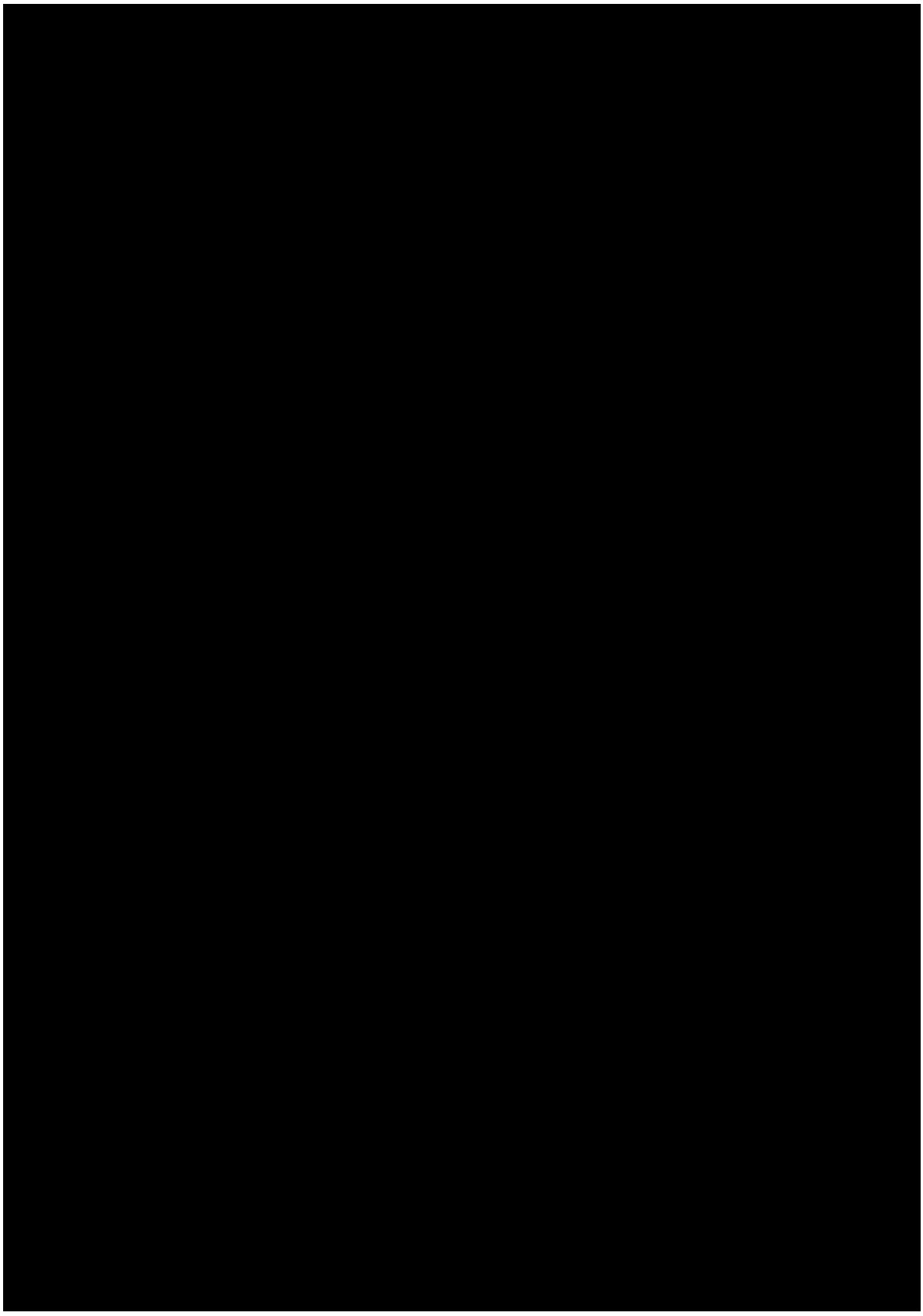
Appendix A contains copyrighted material that the library was unable to obtain permission to reprint. The assessment tools in this appendix can be found in:

Gail Steketee, Randy O. Frost
Treatment for Hoarding Disorder: Assessing Hoarding Problems. Copyright © 2013 by Oxford University Press









Appendix B

Shareable Resource: Current United States Hoarding Task Force List with Active Links

State	County	PDF	Hoarding Task Force Websites (updated 6/16/2022)
Arizona	Maricopa / Northern AZ / Pinal / Southern AZ / Verde / Yavapai / Yuma		https://sites.google.com/site/arizonahoardingtaskforce/
	Pinal		https://sites.google.com/site/arizonahoardingtaskforce/home/pinal-county-chapter
	Southern AZ		https://sites.google.com/site/arizonahoardingtaskforce/home/southern-az
California	Orange County		
	San Bernadino		https://ecobear.co/knowledge-center/support-groups-for-hoarders-in-san-bernardino-county/
	San Francisco	https://mentalhealthsf.org//documents/Task%20Force%20Report%20(FINAL).pdf	https://www.mentalhealthsf.org/san-francisco-task-force-on-compulsive-hoarding/
	San Mateo County	https://www.smchealth.org/sites/main/files/file-attachments/hoarding_brochure_10..pdf?1468945904	
	San Diego	http://ocdsocal.org/wp-content/uploads/2014/04/SDHC-Resouce-Directory.pdf	
	Los Angeles	http://file.lacounty.gov/SDSInter/dmh/159929_hoarding_fact_sheet.pdf	

		http://file.lacounty.gov/SDSInter/dmh/216946_Guidebookforonline.pdf	
Colorado	Colorado Hoarding Task Force		https://www.coloradohoarding.com/about-us
Connecticut		https://portal.ct.gov/-/media/DMHAS/Publications/StateAgencyResponseforHoardingpdfpdf.pdf?la=en	
	Newington	https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/dph/environmental_health/HH/Hoarding/MMHoardingOverviewPOSTJune212016pdf.pdf?la=en	
Florida	PASCO		https://www.pascocountyfl.net/2846/Hoarding-Task-Force
Georgia	Livingston		https://www.livgov.com/hscb/Pages/LC-Hoarding-Task-Force.aspx
Hawaii		http://www.honolulu.gov/rep/site/dcs/eaddocs/apdec2007.pdf	
Illinois	Kane		https://www.kchoarding.org/
	DuPage	file:///C:/Users/lesli/Downloads/Hoarding%20-%20How%20to%20Help%20Through%20Recovery%20(3).pdf	
	Chicagoland		https://chicagohoarding.org/
Kansas	Sedgwick		https://www.sedgwickcounty.org/hoarding-coalition/

Maine	York	https://www.hoardingme.org/hoarding-resources.html	https://www.hoardingme.org/
	Portland		https://www.hoardingme.org/hoarding-resources.html
Maryland	Montgomery County	https://www.montgomerycountymd.gov/HHS/Resources/Files/Reports/finaltaskforceonhoardingbehaviorreport.pdf	
	Gaithersburg		https://www.gaithersburgmd.gov/services/community-services/hoarding-task-force
Massachusettes	Barnstable		https://www.hoardingcapecod.org/
	Merrimack Valley		https://www.esmv.org/programs-services/hoarding-and-cluttering/
	Abbington	https://www.abingtonma.gov/sites/g/files/vyhlif236/f/news/hoarding_task_force.pdf	
	Brookline		https://www.brooklinema.gov/513/Hoarding-Task-Force
	Glouster		https://www.gloucester-ma.gov/202/Hoarding-Taskforce
Michigan	Livingston	https://www.livgov.com/hscb/PublishingImages/Pages/LC-Hoarding-Task-Force/LC%20Hoarding%20Task%20Force%20Guidelines.pdf	https://www.livgov.com/hscb/Pages/LC-Hoarding-Task-Force.aspx
	Grand Rapids		https://www.grandrapidsmi.gov/Government/Programs-and-Initiatives/Grand-Rapids-Area-Hoarding-Task-Force

	Saginaw County		http://www.hoardingtaskforcesaginaw.org/documents/Hoarding%20White%20Paper.docx
	Washtenaw	http://htfwashtenaw.org/yahoo_site_admin/assets/docs/Hoarding_Fact_Sheet.9891600.pdf	http://htfwashtenaw.org/
Minnesota		https://img1.wsimg.com/blobby/go/d3cb282e-0498-4fbc-b1f6-dcccd5fb3c05/MN%20Hoarding%20Task%20Force%20Comprehensive%20Reso-0005.pdf	https://mnhtf.org/?fbclid=IwAR3HmaRnR6Kfn0XClkbmHua_B0qowGybEkrqMjKqqrniurVfMj-MaVzHDrc
Mississippi			https://www.researchgate.net/profile/Mary_Dozier3
Missouri		https://www.springfieldmo.gov/DocumentCenter/View/3185/Multi-Disciplinary-Hoarding-Risk-Assessment-PDF?bidId=	
Montana	Missoula		https://missoulahoardingtaskforce.com/
New Jersey	Atlantic County		http://www.mhaac.info/htf.html
New York	New York City	https://www.nysenate.gov/sites/default/files/articles/attachments/HOARDING_BOOKLET_FINAL_LK_approved_nonbooklet.pdf	
North Dakota	Cass County - Fargo		https://fargond.gov/city-government/departments/fargo-cass-public-health/environmental-health/hoarding/fm-hoarding-coalition-fmhc

Ohio	Stark		https://starkmhar.org/programs/coalitions/hoarding-coalition/
	Cuyahoga		https://www.hoardingconnectioncc.org/
	Summit		https://www.admboard.org/hoarding-task-force.aspx
Oregon	Multnomah		https://multco.us/ads/multnomah-county-hoarding-trainings-task-force
Pennsylvania	Alleghaney	https://apps.pittsburghpa.gov/redtail/images/1353_Resource-Guide-2017.pdf	
	Philadelphia		http://www.philadelphiahoarding.org/
	Delaware		https://www.delcosa.org/AGISModules/ProviderSearch/ProviderDetails.aspx?OrgID=536243&mid=267&pageid=0&letter=D&state=
Rhode Island			http://www.rihoardingtf.ri.gov/
Texas	Houston		https://houstonhoardingnetwork.com/
Utah		https://dsamh.utah.gov/pdf/OA%20Conference/Utah%20Hoarding%20Disorder%20Interventions.pdf	
Vermont	Rutland	https://dcf.vermont.gov/sites/dcf/files/OEO/training/Hoarding-Issues.pdf	
Virginia	Fairfax		https://www.fairfaxcounty.gov/code/hoarding
		https://www.cga.ct.gov/2010/rpt/2010-R-0483.htm	
Washington	Tacoma	https://iocdf.org/wp-content/uploads/2015/05/Hoarding-Project-	

		Tacoma-Description.pdf	
West Virginia	Morgan Town	https://www.morgantownwv.gov/DocumentCenter/View/482/Hoarding-Brochure-PDF	https://www.morgantownwv.gov/303/Hoarding
Wisconsin	Portage	https://www.co.portage.wi.us/home/showdocument?id=20287	https://www.co.portage.wi.us/department/health-and-human-services/division-of-community-programs/hoarding-task-force-of-portage-county
	Milwaukee		https://milwaukeehoarding.weebly.com/
	Stevens Point		https://stevenspoint.com/1299/Hoarding-Task-Force
	Eau Claire		https://www.eauclairewi.gov/government/our-divisions/health-department/there-s-more/hoarding-task-force-of-eau-claire-county
Wyoming	Wyoming Center on Aging recource guide refers to Colorado Hoarding Task Force		https://www.uwyo.edu/wycoa/_files/brochures/hoarding-resource-guide-2018_kb.pdf

Appendix C

Survey Participant Job Titles

Administrative Analyst
Adult Protective Services Supervisor
Assisted Living Case Manager / Senior Liaison
Attorney
Chief Operating Officer
Community Collaborative Planner
Director of Hoarding Intervention and Treatment Program and In Home Support Program
Enforcement Officer
Enforcement Director
Fire Inspector
Forensic Manager
Health Inspector
Professional Organizer
Professional Organizer with specialized training in Hoarding/ADHD/Industry Certifications
Professional Organizer with Social Work/Mental Health / Industry Certifications
Program Manager
Real Estate Relocation Specialist
Resident Service Coordinator and Housing Stability Specialist
Resident Support Specialist
Senior Environmental Specialist
Senior VP Operations
Service and Support Coordinator
Strategic Program Director
Supervisor Hoarding Intervention Program

Appendix D

Hoarding Task Force Member Survey

Hoarding Task Force Member Survey

Pilot Research Study - Leslie Hatch Gail, M.Ed. - National Louis University

Informed Consent

Informed Consent Online Survey

You are being invited to participate in an online survey for Dissertation Research being carried out by Leslie Hatch Gail, M.Ed., a PhD student at National Louis University. The study, "Factors that Influence Hoarding Task Forces: Evaluating Organizational Culture," is taking place from 11/2021-4/2022.

You were selected to participate because you are currently a member of a hoarding task force in your community. The purpose of this study is to gain a deeper understanding of the viability of hoarding task forces by considering practices/polices, operations, leadership, and beliefs about people living with hoarding difficulties among members of established hoarding task forces.

Participation in this study will include completion of the following online survey, expected to take approximately 15 minutes.

Your participation is voluntary and can be discontinued at any time without penalty or bias. The results of this study may be published or otherwise reported at conferences and employed to inform hoarding task force practices in the future, but participants' identities will in no way be revealed (data will be reported anonymously and bear no identifiers that could connect data to individual participants). To ensure confidentiality the researcher's data file of compiled results will be kept in a password protected folder on an internal university workspace for at least three years until it is deleted by the researcher. Only Leslie Hatch Gail, M.Ed., will have access to data. There are no anticipated risks or benefits, no greater than that encountered in daily life. Further, the information gained from this study could be useful to establishing and maintaining successful hoarding task forces.

You may receive a summary of the results from this study upon request and copies of any publications that may occur. Please email the researcher at [redacted] to request results from this study. If you have questions or require additional information, please contact the student researcher, Leslie Hatch Gail, M.Ed., by email or phone [redacted], or her primary advisor, Dr. Bradley Olson, bradley.olson@nl.edu, IRB Co-Chair, Dr. Christopher Rector, crector@nl.edu, or IRB Chair, Dr. Shaunti Knauth, shaunti.knauth@nl.edu.

Thank you for your consideration.

Consent: I understand that by checking 'Agree" below, I am agreeing to participate in the study, "Factors that Influence Hoarding Task Forces: Evaluating Organizational Culture." My participation will consist of the activities below during 11/2021-4/2022 time period: Completion of an online survey taking approximately 15 minutes to complete.

1. ELECTRONIC CONSENT: Please select your choice below. You may print a copy of this consent form for your records. Clicking on the “Agree” button indicates that • You have read the above information • You voluntarily agree to participate • You are 18 years of age or older *

Mark only one oval.

Agree *Skip to section 2 (Hoarding Task Force Member Survey)*

Disagree *Skip to section 7 (Participation Declined)*

Section 1

This survey requests your perspective about the organizational culture of your Hoarding Task Force. The items pertain to practices, operations, leadership, and beliefs. The survey consists of four sections, concluding with a series of demographic questions. Thank you for taking the time to complete this survey.

Section 1: Multiple agencies work together to address compulsive hoarding in communities. The formation of a Hoarding Task Force is a way to coordinate these responses. Please respond to the following items about the practices of your Hoarding Task Force.

2. Our hoarding task force has a stated purpose.

Mark only one oval.

Yes

No

Our task force has a mission or stated purpose, but it needs revision.

3. Our Hoarding Task Force has regularly scheduled meetings.

Mark only one oval.

Yes

No

4. Our Hoarding Task Force provides professional training/education programs. *Mark only one oval.*

Yes

Yes, but programs are temporarily suspended due to global

pandemic restrictions. No

5. If your Hoarding Task Force provides professional training/education programs, what topic would you like to see covered more?_____

6. What best describes the compensation for your role in your Hoarding Task Force? *Mark only one oval.*

The services I provide are compensated as part of my regular job description. I receive a stipend for the services I provide.

I volunteer my time and expertise.

Other:

7. Our hoarding task force interventions begin with a health and safety assessment. *Mark only one oval.*

Yes

No

Some of our members begin their interventions with a health and safety assessment.

8. Did the leader of your Hoarding Task Force volunteer for the leadership position? *Mark only one oval.*

Yes

No

Our leader was assigned.

9. I am the leader of our Hoarding Task Force.

Mark only one oval.

Yes

No

Our task force does not have a leader.

10. Skills necessary for a successful Hoarding Task Force leader: (Check all that apply) *Check all that apply.*

Balances leadership role with work tasks
Detail-oriented
Enforces task force policies and procedures
Identifies and coordinates resources
Initiates community outreach
Innovative ideas
Organizational capacity
Secures funding
Sensitivity and awareness of evidence-based hoarding practices
Team-oriented

11. The strengths of your Hoarding Task Force are: (Check all that apply)*Check all that apply.*

Assessment process
Communication across agencies
Community Outreach
Education and training opportunities
Funding sources for hoarding task force services
Leadership
Marketing and Public Relations
Member expertise
Person who hoards is at center of effort
Referral networks and/or resources
Volunteers
Other:

12. The challenges for your Hoarding Task Force are:

(Check all that apply) *Check all that apply.*

Assessment process
Communication across agencies
Community Outreach
Education and training opportunities
Funding sources for hoarding task force services
Leadership
Marketing and Public Relations
Member expertise
Person who hoards is at center of effort
Referral networks and/or resources

Volunteers

Other:

Section 2

Section 2: Please respond to the following items about membership in your Hoarding Task Force.

13. Our Hoarding Task Force members have similar priorities and goals for our people living with severe hoarding difficulties in our community.

Mark only one oval.

14.

When I have a problem with a hoarding task force related issue,
I can talk about it with members of this task force community.

Mark only one oval.

15. Members of this hoarding task force community can count on each other.

Mark only one oval.

16. I put a lot of time and effort into being a part of this hoarding task force community.

Mark only one oval.

17. This hoarding task force community has good leaders. *Mark only one oval.*

18. This hoarding task force community has beneficial information to share with other hoarding task force communities.

Mark only one oval.

19. Based upon your experience, this Hoarding Task Force has been successful in meeting the needs of people living with severe hoarding difficulties in your community.

Mark only one oval.

20. I expect to be a part of this hoarding task force community for a long time. *Mark only one oval.*

21. I feel hopeful about the future of this hoarding task force community.

Mark only one oval.

Section 3

Section 3: This section pertains to people living with severe hoarding difficulties. By severe hoarding difficulties, we mean people who keep large numbers of possessions in active living areas to an extent they cannot use rooms as intended (e.g., using the kitchen to cook, bedroom to sleep).

22. Thinking in terms of overall psychology or personality, how similar do you think a person with severe hoarding difficulties is compared to the average population in the United States?

Mark only one oval.

23. Thinking in terms of overall psychology or personality, how respected do you think a person living with severe hoarding difficulties is compared to the average population in the United States?

Mark only one oval.

24. Thinking in terms of overall psychology or personality, how responsible do you think a person living with severe hoarding difficulties is for his or her condition?

Mark only one oval.

Section 4

Section 4: The final eight items will help put your responses in context by requesting some information about you.

25. Department / Organization / Field (check all that apply)*Check all that apply.*

Adult Protective Services

Animal Resources

Attorney / Legal

Child Protective Services

Cleaning / Restoration

Code Enforcement

Family Member of person living with severe hoarding difficulties Fire Department
Law Enforcement

Mental Health / Therapist

Professional Organizer

Real Estate

Social Work

Volunteer

Other:

26. What is your current job title within your department / organization / field?

27. Highest level of education completed

Mark only one oval.

High School or equivalent

Associates Degree

Bachelor's Degree

Master's Degree

Doctoral / Professional Degree

28. How many years have you been a member of this hoarding task force? *Mark only one oval.*

20+ years

11-20 years

6-10 years

3-5 years

0-2 years

29. In the past 12 months, approximately how many people living with hoarding disorder did your Hoarding Task Force provide services to?

Mark only one oval.

More than 50

25 - 50

10 - 24

0 - 9

Not sure

30. Approximately how much time per month do you spend working on Hoarding Task Force related projects?

31. In which state in the United States does your Hoarding Task Force provide services?

32. Are any of your friends/family members currently challenged, or have they ever been challenged by hoarding difficulties?

33. Is there anything else you would like the researcher to know about your Hoarding Task Force?

34. You have completed the survey. If you are interested in participating in future research on Hoarding Task Forces, please provide your contact information (email and/or phone number) below. Thank you!

Participation Declined Elected not to participate

Appendix E

Informed Consent for Hoarding Task Force Member Interviews

You are being invited to participate in an interview for a Dissertation Research Project being carried out by Leslie Hatch Gail, M.Ed., a PhD student at National Louis University. The study, "Factors that Influence Community Responses to Hoarding: Evaluating the Organizational Culture of Hoarding Task Forces, Sense of Community, and Definitions of Successful Outcomes," is taking place from 11/2021 - 4/2022.

You were selected to participate because you are currently a member of a hoarding task force in your community. The purpose of this study is to gain a deeper understanding of the viability of hoarding task forces by considering practices/policies, operations, leadership, and beliefs about people living with hoarding difficulties among members of established hoarding task forces.

Participation in this study will include responding to semi-structured and demographic interview items. The interview items ask about experiences and expectations for those receiving

assistance for hoarding, best practices, treatments for supporting a person living with hoarding challenges, and how to define successful outcomes. The interview will be conducted virtually and is expected to take approximately 45 minutes.

Your participation is voluntary and can be discontinued at any time without penalty or bias. The results of this study may be published or otherwise reported at conferences and employed to inform hoarding task force practices in the future, but participants' identities will in no way be revealed (data will be reported anonymously and bear no identifiers that could connect data to individual participants). To ensure confidentiality the researcher's data file of compiled results will be kept in a password protected folder on an internal university workspace for at least three years until it is deleted by the researcher. Only Leslie Hatch Gail, M.Ed., will have access to data. There are no anticipated risks or benefits, no greater than that encountered in daily life. Further, the information gained from this study could be useful to establishing and maintaining successful hoarding task forces.

You may receive summary results from this study upon request and copies of any publications that may occur. Please email the researcher at [redacted] to request results from this study. If you have questions or require additional information, please contact the student researcher, Leslie Hatch Gail, M.Ed., by email or phone [redacted], or her primary advisor, Dr. Bradley Olson, bradley.olson@nl.edu, IRB Co-Chair, Dr. Christopher Rector, crector@nl.edu, or IRB Chair, Dr. Shaunti Knauth, shaunti.knauth@nl.edu.

Thank you for your consideration.

Consent: I understand that by checking 'Yes" below, I am agreeing to participate in the study, "Factors that Influence Community Responses to Hoarding: Evaluating the Organizational Culture of Hoarding Task Forces, Sense of Community, and Definitions of Successful Outcomes."

My participation will consist of the activities below during 11/2021-4/2022 time period: Participation in a virtual interview taking about 45 minutes to complete.

Appendix F

Interview Transcript Sample: Hoarding Task Force Member CAWI5

How did you become involved with your hoarding task force?

The task force had just organized, and they were looking for a chair. I was already known in the community for helping people with hoarding disorder. So, I was asked to be the chair.

Perfect. Okay. And then how has being a part of the taskforce affected your approach? How has it affected your approach to providing services to people living with hoarding challenges?

Um, I think it has affected where I know who's who in the zoo, where to utilize certain resources. Which figures of the task force are more of, for putting on pressure to people, and which figures in the test scores are more of the supportive people when you're doing kind of like good cop bad cop situations? And who is able to get specific other types of resources or make things happen. Like if we need somebody who has someone who is failing different kinds of inspections, we utilize the city inspection people, someone that we know, someone who is part of our task force is that get them on the case? Somebody who has an understanding of the hoarding disorder, or like if somebody needs a dumpster or something like that,

we're able to get everyone together.

What is your department? Or what do you consider your field?

I am director of hoarding intervention and treatment program at [redacted] *and a director of in-Home Support Program.*

How does being in that position of Director shape your approach to helping people with hoarding challenges?

Well, it helps because I understand where what goals need to be met with people in regards to emotionally, financially, with their environment. And I'm able to, kind of, from all the experience that I've had, share my experiences and things that have worked things that haven't worked. And then just with networking, who like at certain agencies has more of an understanding. So, I will have my case manager contact specific people in agencies that understand not just have like, gone through one of our trainings, but who is on the same page with actually what we're trying to get accomplished with, with our clients.

Okay, that makes sense, because you can delegate

Everyone on our team serves clients, I have clients too.

Okay

So, I've never stopped with clients. And that's how I actually started the program is with the In-Home Support program we've always had and long-term care. I've always worked with people with hoarding disorder with homecare.

That was my next question, prior experiences, so you can keep talking about that?

Yeah, I've always. For the last 26 years, I've worked in long term health care, and in different settings, nursing homes, to group homes to a lot of home care. So, I've always, always come across people with hoarding disorder doesn't matter if they're in their house or if they're in a nursing home. And I've always worked with those people hands-on because I've seen to have had success with them where agencies really quick to write someone off. Their employees are told to ignore the hoarding that's going on or to do something drastic, like throw their stuff away. I've always had approaches that work with people. So come into work at [redacted] *being director of In-Home Support Program, because we work with on a sliding fee scale, and people with hoarding disorder, most times having financial issues. So, they would come into our program, I would just start serving them. And then I had a discussion with the executive director and how to make working with those with hoarding disorder, its own program, and how that would best look with best practices and approaches. So, like, it's been seven, more than seven years, that we started putting together white paper. And some of the cases that we had been, I'd been working on and put it together and then presented it to our funders, and which our biggest funders* [redacted] *They're completely on board. Because all the other programs that* [redacted] *funds, the people from those agencies all said they need to for referrals, because they all deal with people with hoarding disorder also.*

Right.

And because essentially, we're preventing homelessness, um, you know, to show the statistics on all of that, and how costly it is for the city, for inspectors, social workers, health departments to deal with this. And if it's not dealt with proper way, of course, it's just going to keep going in a cycle and costing the city more and more instead of putting the money towards actual program that works.

When someone reaches out to the hoarding Task Force, at what point do you become involved?

For the task force, what usually happens is, everyone on the task force knows that we have an actual hoarding program so they will call us. And then usually, they're dealing with this person that has hoarding disorder also in some fashion. So, when we get together in the task force, we share resources and any kind of educational information. And that's more of what our task force is, is to get the word out there, especially with people who are isolated. So are the nurses on the task force through our county will share information. And they will give us everyone will share updates for resources, but then they know to direct an offer, if somebody wants to start a program for you know, for help that then they referred over to, to [redacted] *to our program. And sometimes people don't want help, right, which then the task force will do a lot of problem solving and different approaches, people in the task force will, but may have gained the trust of someone but they're not willing to have help. So that's the thing with the people are in the task force are willing to do hands on work, where instead of it's, they understand that the people who are in the task force understand that they're the ones who understand it. And sometimes there's no one else to help and the client is not accepting but if they're working on certain goals, these people are willing to do hands on where and then when someone comes to you, you know, you get a referral, and someone's ready to work.*

How long do you then work with someone?

It's kind of ongoing, but yeah, well we work with people as long as they are meeting goals. So, we do good criteria. We come out, we assess them because for our program we do not to things we do not do is work in homes where there's biohazard material, and no bedbugs infestations

Right?

Yeah, our staff don't like that. So, the case manager goes out and assesses. And then the client is assigned. They have the case manager, okay, and home therapist, and a home coach.

So, all three of them meet with the client, the client comes up with their goals, we kind of help them with goals, if they can't think of it, and we make safety number one. Once we've taken a look at their home, if there's something very specific in regards to safety, they need to take care of. So, they got like big goals, and then they got smaller goals to work on. Then the assessment is not just assessing the house, but their health, finances, and social network. That's great. So the case manager, then behind the scenes will help connect them with like, making sure they're taking care of their health, whatever issues coming up with finances, social network, the home coach will then go into the home two hours once a week, to help them start to declutter, start to kind of make sense of what's behind the hoarding. Like, is it more OCD? Is it just depression? And they start to get them to change their behaviors and instill new coping skills.

You go in as a coach.

Yeah, I do.

And then we do have a therapist that goes into the home, and the therapy is done in the home.

Oh, wow.

That sets us apart from regular therapy. And the therapist also helps them too, with their, their coping, because hoarding is just a way of coping with thoughts and feelings. The therapist works

with them on establishing new coping behaviors, healthy ones. The therapist sees them once a week, in their home for an hour, home coach two hours once a week, the case managers kind of like behind the scenes, kind of looks over the care plan. We do like beginning pictures. And then as they start to work on areas and meet goals. Again, they're they work with us as long as they're going forward. If they start to undo what we've done, we usually give them like two or three chances to have a different approach, see if something else works. But essentially, if they undo what we have done, then they will get put back on the waiting list until they're ready for change. Just like any other kind of treatment program, you have to be actively working at that change. To change up your daily behaviors. You have to do it constantly. And it's a good boundary. Because then you can identify this has happened and we're putting you back on the waitlist.

Okay. Yeah.

But all the excuses that people would give us to not be able to tend to their, their hoard is what case manager will be working with him. So, if they say, I can't do this, because I have bad knees, well, let's take care of them bad knees. Or I can't do this because I'm worried about paying this bill. Well, then we Case Manager works on them and their bills. So, we have a net in place to combat any kind of excuses someone will come at us with. And that's where we have success. What we call all the wellness factors that were it's essentially a wraparound program.

What have you learned about outcomes for people living with hoarding challenges?

Outcomes are different dependent on what their overriding diagnosis is that's fueling their hoarding. So, we find those who come to us that have more depression, they clean up and clear up quicker that depression is lifted, their outcome outcomes and ongoing is looks really good. And they just kind of clear up quick. There are the outcomes that we measure. One is that they're willing to discuss hoarding disorder and accept that that's what they have, and that they are

accepting us to come into their home to help them. So, there's like, some of those short-term outcomes that we measure. And then we have measurements of outcomes of clearing up all safety risks. So sometimes we can clear up people's safety risks, but their home is still essentially got a lot of clutter in there. Because just by having a lot of clutter doesn't mean it's completely unsafe. So, we measure that. And then we measure those who successfully complete the full program, which is 75% of our clients.

That's impressive.

Yep. So, the time that they're with the program, I said, it can be different. Some people like that have more depression clear up quicker, usually within six months. Those who have more anxieties or OCD behaviors, we have to work longer with to work on retraining the brain, and, you know, getting in new routines, it takes a long time to establish a new routine in someone's daily living. And then, you know, throughout a year, there's usually a couple setbacks, it could be a health setback, or a pandemic, loss of loved ones, because we're dealing with older people, people die in their lives. So, then there's usually some setbacks. But all depends on how much stuff they got to, we got people who are ran studios, we have people who have a couple houses and some storage units, slow. But it is at a slow pace. And as long as they're going forward, we will continue with them.

Have your expectations regarding outcomes changed over time, since you first started working with people?

I don't know, I think we just have realized how to quickly figure out if someone is ready for our program. Instead of having them on our program in utilizing a lot of resources and really trying to come on, you can do this. We can figure that out quicker. So, we can let them know. You're not

ready for the program. And since the day we started our program, we've had waiting lists. And we serve about 60 Some people at a time. And we have a waiting list of close to 100.

Wow. The word is out.

Yeah, and a lot of people may hear of our waiting list. And so, if you're looking for treatment, and you're like oh my god, I'm ready for change right now. And then you call in then you're like, I want to start. And you know, your treatment centers like Sorry, there's a waiting list and may take six months to a year to start. And then people get depressed, they fall back into No, kind of throw up the towel. So that's the unfortunate part about this. But that's why we measure at least those who are willing to call and say hey, there's a problem. And I want help. And you know, we capture those numbers to show our funders that there's so many people who want help. The thing is they want help from someone who understands their diagnosis, someone who has experience with helping success, and someone who, you know is not going to look down at them or treat them with any kind of stigma. Because that's the biggest problem was all the stigma around. But, you know, the show has that brought it to light. And, you know, people Google [redacted] *we're the only program that really comes up. So, we have calls from all over the country, every day, really, and we do have support groups. And people don't have to be in our programs to people can reach those outcomes if they have special specialized care.*

Is there a fee for the support groups?

Oh, no. That's, that's why we get the [redacted] *Yeah, we can utilize.*

We have interns, therapy and turns that will help us with the support groups. So, we don't have to have to bring on too much more staff for that. And that's only once a month.

To shift gears a little bit, what can you share about the role of family members in supporting a person who hoards?

Um, so it all depends on the family. Usually, what we have to start off with and kind of part of our starting our services is education. You know, they may have like, read some little bit about hoarding. But many of them have a lot of resentment, because it's been going on for so many years. But I think once they understand how we're approaching it, and we make them part of our team, like I say, sometimes again, I have good cop, bad cop. And sometimes they can play either one of those roles. And they're usually fine with playing bad cop because they just want to see their family member in a safe place. So sometimes we have to use them for that, you know, to put the pressure on to get them to change. So, they are usually a good part of the team that we need. They're good to get us information like back information, instead of us having to spend six months of digging through stuff to really figure out hey, she'd lost a child way back in the day. And this is when this all started. A family members can usually kind of bring us up to speed a lot quicker than our clients can. But sometimes family members get in the way. And we have to let them know that. And of course, they feel like they don't want to look like they haven't done anything we understand they've probably tried for years. So that's why we have two support groups, one for individuals with hoarding disorder. Right now, we have one support group for family and friends of those who have hoarding disorder. So, as we always recommend that the family and friends when clients are starting at least attend one of those support groups. And then we send them information in education to simple things for them to understand, not like what's Googled, but we do like a simple fact sheet. And kind of put it in terms that they can understand. Like, instead of having a discussion about hoarding disorder, we'll have a discussion about addictions. And then they can relate better to a discussion like that. So yeah, friends and family, a lot of times they're needed because we need information or finances. We need someone who, after we're out the person will need like, ongoing help with making sure bills are paid, and

making sure they're going to the doctor's appointments. And then family members will call us if someone's backsliding. You know, they'll tattle.

Right.

But a lot of our clients don't have any family or anyone who is left to help them out. A lot of our clients have lost children just don't have family around anymore. I would say at least a good third. Hard situations is when we have numerous people in a household that have hoarding disorder. And ones who are ready and months writing ones not Yeah, those are hardest situations. We have a couple that it's like a parent and a child. I mean, the child's like in their 40s. But yeah, they're very defensive. They blame each other. Or if there's spouses that are doing it, too, they blame each other. And those are usually our hardest situations. So, we look at those goals more of in terms of safety, because overall, clearing up all the clutter, may not happen.

Right. That's an important point.

We just have to understand and what we remind ourselves is that this is it's a mental health issue that they will always have to work deal with. It's never going to magically go away. And so. So, some people are ready and can change and some can't, you can't, can't win them all, even if we've worked hard in there.

What have you learned is the most effective treatment for hoarding disorder?

Well, the most effective treatment is a wraparound. It is someone who's addressing their physical health, their financial health, the environment, health, and their social health. Those are the four main things that the higher that we bring those wellness levels, then you'll have more success, if you only treat the physical health, and just the environment. Those other and not the other two things, they're going to become excuses for them to, to relapse, or to go backwards, just like any

other kind of addictions. So you got to try to help them get ahead with as many problems or issues that they're having in their life, to give them more success.

And that's literally the next question is the criteria for success. But you already answered that is to be having success in the four different areas.

Yeah, in the four different areas and successes, the goals they put, sometimes, yes. Sometimes their goal isn't to clear up the whole house, which is fine, as long as it's safe. And they are reaching the goals that they have, then we're teaching them how to change up those behaviors. And the therapists working with their coping and their mental health. So um, and with those with the illnesses, I don't include, because it's some we're already there working with the therapist. So, it is making sure wellness and the mental health is, of course, has increased. So that is, of course, the most important is the mental health part of it.

But there are, you know, specialized like inpatient treatments for hoarding that I found. So if you think about it, you can go in patient for your hoarding disorder. Get all this therapy, all this discussion. They're like, okay, treatments over you're good, you know what to do. And then you go back out the door, and then you're in front of your door, you open it up and you had a house filled with stuff. We've had a lot of people who've done inpatient treatment for hoarding disorder and then come to us. I have not heard of it helping anyone. So, you they have to fit, nobody could get out of their hoarding disorder alone. And that that is in general is what we've learned. No one can do this. Yeah, that makes sense the magnitude of what they have to accomplish yeah with all the not just the physical book, the mental health be like, following up with things. There's a lot of follow up and when you're overwhelmed, then you have all every buddy with hoarding disorder is overwhelmed, they got a lot going on. They cannot slow down to focus and take care of all these tasks to bring them up. They may take care of one but then they lack in those other

areas. And so then it just keeps going. It's the sauce unless you bring them all up that level of wellness and all those factors at once.

What would you say are some positive attributes of having hoarding disorder? We always look at what they're not doing or what they need to improve on.

They're able to hyperfocus you give them one task, and they can do that. But if you give them 10 tasks, they can't do 10 tasks. They can only focus on one and they will work on one really good. That's why you just got to follow up with them with the next one. Well, okay, great. But they are the smartest people that I know. Most of the people that we work with, that have hoarding disorder, a lot of them at some point in life were very successful. A lot of professors, a lot of doctors, we have lawyers, pharmacists, people who are able to hyper focus, you know, very knowledgeable and can sit down and think like crazy stuff I can never comprehend. The thing is, they can be really good at one thing and knowledgeable. But then they laugh in the other areas because they don't know how to balance out those thoughts. So, the good thing is that they will, if you can channel their ability to problem solve, into their daily living, then they're like, then something will click. They have to be able to, they just need you to kind of like be the mediator like this is how you problem solve with this because you already know that promise, is like the angel and devil on their shoulders. You know, they'll have that one voice that says Okay, keep this you can use for this you can you got all these and then you know you got the other voice that's like, well, you don't need this, you should toss it out. They it's either a stronger voice on one or the other. So sometimes we have people who will have the voice that will be like, get rid of it all. And we have to stop them. So sometimes we have to stop them from throwing out too much. It's because it is like I said, they're so polar with those thoughts. It's about balancing it out. Some people start tossing and toss out and important things and I have to stop and I'll be like, no, let's

not throw these things away because you need these things. So, it's trying to get them to balance out that thought process. But even one thing they can do really good with whatever they've done in life. As I always start with our clients and having them share with me, things that they can teach me, then we can trust that we gain the trust like that. They can see that I respect them. They've done whatever in life and that they're just overwhelmed. Not that they're stupid or anything. They're super smart. And when we go through their stuff I'll bring up and all the home coaches are very good at them. And be like 'Dang, you have a really good eye for the antiques.'

Right

So that's all part of process of when we're clearing out things is making them feel part of the process and like their stuff matters. But usually, our clients are going through a lot of depression. Those are the homes that are filled with garbage. So, we don't have to go through all that stuff, but we still watch because their state of depression. There's usually money and checks and some of that but they haven't paid their bills, but they've got like $1,000 in cash like in the garbage. So, but they clean up quicker. We just have to kind of be very vigilant of what's going on. Because they're almost not dealing with it. Yeah, yeah. They just didn't care. That's why they toss it down, but they know it's garbage. And that's the thing is that everyone that we treat, is aware they have a problem. They all know it. So, the stigma about all they don't know or don't know that, that this stuff is covered. No, they all know it. And they know it's having a negative effect on them. It's just that within the addiction they're defensive. They'll come up to you with excuses. And if they don't know that there's help out there. They're going to be even more defensive. But they know there's a problem and they don't want to live like that. It's just too scary for them. thing. How they're going to call the night that they don't have their stuff.

That was all my formal questions for you. Now we're at the point of if there's anything you wanted to add that you feel is important for me to know about your experience or about hoarding.

Would be very good to note that with pandemic, I expect these numbers, the numbers that we already have, or statistics say like 6% of the population of the 6% Right? easily they can double because hoarding disorder. What they say is, you know, what's caused by causes the mental health issues is, you know, loss of loved ones, loss of jobs, those who have anxieties and fears, so those with OCD are even more OCD. A lot more isolated. That's a pandemic, people are isolating more. They're disconnecting from family. They're in their homes, they're disconnecting from reality. In their loved ones are dying from COVID and whatever else is going on. So, and then the thought of what you do when you don't have money, you start holding after things. So, more programs. That's why I go, and I will talk wherever people want me to talk I'm not trying to hold on to any secrets too hard. Because we can serve everyone. But the numbers are going to double Easy, easy, the numbers are going to double and it's the whole population that are now homeless. We're dealing with repeated reactive to problems of homelessness instead of proactive and dealing with people with mental health issue hoarding disorder, but it's no secret that mental health problems are increasing too. But in general, hoarding disorders are likely to be very high. It really does take that wrap around with some that involves a very delicate balance people to to have something to bring that sense of community within your own room. The hardest part about this is finding the right people to serve to do the job. We are not getting rich, but the staff that I have on most of the staff are people that I know that already have life experiences said they're more like peer support have mental health knowledge willing to work in homes that are filled with crap. And it's not easy. So, my approach with staff is different than maybe a different

approach. Like programs or jobs. It's because I truly make them their own team. No one's overseeing another person. If they're having a bad day, if they don't have patience. You can reschedule a client. I'd rather that you burn yourself out because for now could be extreme. Or, you know, you could upset a client and with our clients, they try to find any kind of reason.

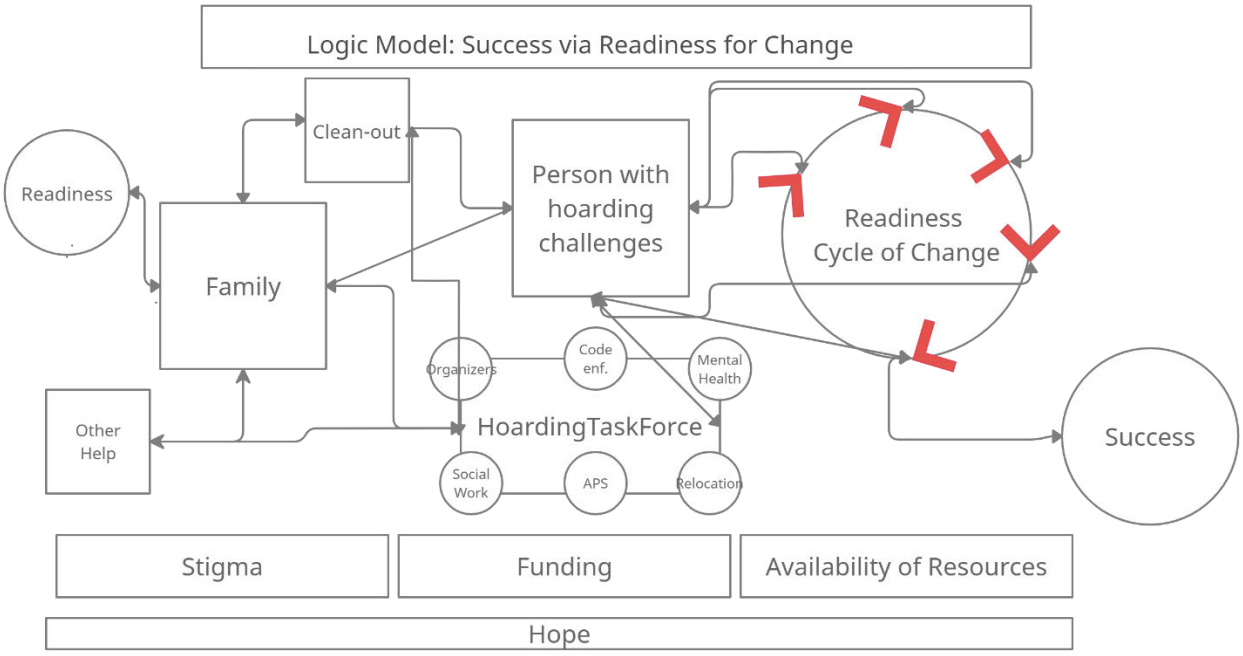
Right.

We have a small team and we've looked at even support to recreate another team. I just don't even know because I truly have to know the people who are going out there. If they're able to handle someone yelling at you falling apart, maybe saying they're going to die without their stuff. And you go into homes and all sudden you're finding diamonds and 1000s of dollars. So, a bad experience for a program really have a negative effect. It's a balancing act. On top of we work allotted not black and white, but in gray. Yes, there is no 'Oh, I do this, and I don't do that.' We'd like to think out of the box.

It seems like it just falls into the category of like community psychology so well because it does. The strength of the people in the community. It's kind of unique to each area. It's like ology, but people have to be willing to put their sleeves up and get dirty. And that's where you don't come across a lot of professionals for funding, and it's hard to find funders are going to fund a boarding program. why these people are just in the hoard again. You know, they'd rather put funding for safe baby sleeping or homelessness, or you know, other things. So, we have to get creative in that sense, and I did just do a training a couple of hours from here. An agency who does like some wraparound cares for people and they are they are actually going to start their own sporting team. So that will be like, but you have to be a client of theirs. program where us it's gentle for the public. But there just needs to be more and it's not a secret. Like we all know how to treat addictions. We know wraparound works; we know we need the mental health. It's

just like the last thing on the board that people are getting behind with proper editing. While they clean out get the word out but that's not almost all of our clients call us then I'm like referred like your mandatory is a voluntary program. So that's a big misconception, right? Are people want help? They just don't they want to be in control. of their services. Oh, you did ask like they pay. Our services are on a sliding fee scale. So, they pay only what they can afford. The only time that is charged them is the time the phone coaches there and that could be like find out. If they're paying, they're not paying for therapy or the case manager. But for the home coach it makes them feel in control of their services and makes them more responsible for their services. Because if you're not there, I'm still going to charge you so there has to be some skin in the game to treatment. And that's how, how we do our program. A lot of little things, but they're still getting through the program. They still utilize what we have to offer.

Appendix G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Clean-out
Readiness
Person with hoarding challenges
Readiness Cycle of Change
Family
Organizers
Code enf.
Mental Health
Other Help
HoardingTaskForce
Success
Social Work
APS
Relocation
Stigma
Funding
Availability of Resources
Hope