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DIGITAL ETHNOGRPAHY AND HOARDING DISORDER:
AN INSIDER'S PERSPECTIVE

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Abstract

Hoarding Disorder (HD), a psychological condition which impacts an individual's ability to discard possessions, affects the well-being of the afflicted individual and those around them. Current HD treatment outcomes demonstrate the need to improve intervention strategies, as many HD clients do not find success with current methods. Though many studies about HD have been done, little research from the perspective of those affected exists. Digital social interactions, via online communities, has provided an alternative platform for individuals in/directly affected by HD to connect and relate their experiences. This investigation used a digital-ethnographic approach to explore online communities of individuals with HD, their friends, family members, and the public, to gain more insider-perspective on HD and how treatment modalities may be improved. This investigation has shown that more emotional-focused support, along with a stronger therapeutic alliance, and public-education surrounding the condition, may improve HD interventions.

Keywords: Hoarding Disorder, Digital Ethnography, AQALS Model

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Chapter 1: Introduction

This thesis represents two decades of living and working across multiple countries and cultures and is founded upon a deep curiosity for finding shared experiences amongst them. This curiosity began in childhood. Coming from an Argentinian background, growing up in Canada and then moving abroad, I developed a deep appreciation for the importance of understanding cultural expressions and values. Listening to the stories of people from various places and backgrounds has shaped my passion for ethnographic research and thematic analysis. One common theme I have noticed across cultures relates to possessions and their importance to people, which may be where my intrigue in Hoarding Disorder (HD) stems from. In this thesis, I aim to combine both Western and Eastern values to help inform a more comprehensive appreciation and understanding of HD. I will begin the paper by providing an overview and background of HD, which will be followed by a review of the literature surrounding the condition. Afterwards, I will illustrate the benefits and rationale of selecting thematic analysis as my methodological approach. The thesis will close with a discussion of my research findings and their implications.

Background

HD is a condition marked by the excessive accumulation of possessions and persistent challenges in discarding them, along with struggles with living conditions and relationships because of the items (American Psychiatric Association, 2013). According to Anxiety Canada (2023), HD affects an estimated 2-6% of the population, making it a common condition. HD is a worldwide phenomenon, affecting people of any age, gender, or socioeconomic status (Frost et al., 2011). The impact of HD on individuals, families, and communities is profound. People with HD experience significant distress and functional impairment, while family members often endure emotional and physical difficulties while

caring for their loved ones (Tolin et al., 2018). Furthermore, HD can lead to social isolation, housing instability, and homelessness, thus affecting the wider community (Ayers et al., 2020). Moreover, therapists often struggle with treating HD clients due to high burnout and low client adherence (Muroff et al., 2017). Therefore, a more enhanced understanding of the condition is needed in efforts to improve support strategies for all involved.

There is a growing body of research investigating HD from various angles. A review of the literature that HD is one of the most publicized mental health conditions (Frost et al., 2011), however, there is an elevated level of misunderstanding of the condition by the public (Muroff et al., 2018). The media portrayal of HD, through shows such as *Hoarders* and *Buried Alive*, has oversimplified the condition, leading to shame and stigmatization of those with HD (Tolin et al., 2008). Moreover, the literature reveals that there is an underrepresentation of the complexities of the condition (Grisham et al., 2005). HD is often comorbid with other mental health conditions, such as depression, anxiety, and attention-deficit/hyperactivity disorder (ADHD) (Frost et al., 2011). Such overlap can exacerbate the difficulties associated with HD, impacting the individual's quality of life, as well as those surrounding them (p. 878). It is essential to recognize and understand the complexities of HD to provide appropriate support and treatment. Currently, Cognitive Behavioral Therapy (CBT) is the most widely used intervention and is regarded as the gold standard treatment of HD (Muroff et al., 2017). However, some authors have pointed out that CBT for HD may not be effective for all patients, with studies showing high dropout and relapse rates, along with low adherence to treatment intervention strategies (Mataix-Cols et al., 2011; Tolin et al., 2015; Tolin et al., 2018). The shortcomings of current treatment approaches for HD not only affect individual clients but also their communities. For instance, neighbors living next to individuals with HD have reported increased pest infestations and unpleasant odors, which can impact their quality of life (Kil, 2019). Furthermore, Tolin et al. (2015) found that 15% of

residential fires were related to hoarding instances, highlighting the potential dangers of the disorder to the community. Unfortunately, social services may also struggle to provide adequate support for HD clients due to limited resources. A literature review by Flett et al, (2016), reported that in Canada, as in the US, there is a shortage of specialized resources and trained professionals available to provide support to individuals with HD. Additionally, the authors suggest that the lack of national guidelines or standardized treatment protocols may also contribute to inconsistencies in service provision.

The Problem

HD is a multifaceted and complex issue, as illustrated by the numerous investigations surrounding the condition and those affected by it. Unfortunately, HD research has several limitations that need to be acknowledged. Firstly, most of the literature has been produced within the Westernized model and perspective on mental health, leading to a gap in collectivistic and Eastern views of emotional well-being (Koç & Kafa, 2019). Additionally, the literature often lacks a client-informed understanding of HD, which includes the first-hand perspective of individuals living with the disorder. This gap in the literature underscores the need for ethnographic studies, which allow for an in-depth exploration of the lived experiences of individuals with HD (Tjørnhøj-Thomsen & Hansen, 2017). Unfortunately, such studies investigating HD are limited or non-existent, leading to a significant gap in our understanding of the disorder. Therefore, the inclusion of ethnographic methods in future research may help to provide a more complete understanding of HD and potentially inform treatment modalities to improve treatment outcomes.

This paper aims to narrow the gap in the current literature by investigating different cohorts of individuals affected by HD. By employing an online, ethnographic approach, observing and understanding the prevalent, shared understandings and experiences of the members of the groups will provide a first-hand experience of living with HD, thus

improving the overall understanding of the condition. Specifically, this investigation aims to absorb the nuance of flow of dialogues amongst group members to discover what benefits group members experience within these groups, which are not found in treatment. This enhancement will afford hypotheses of improved intervention strategies for professionals working with HD clients. The research questions posed within this investigation include:

1. What is the nuance and flow of the online HD communities?

2. What are the key features of participation in online HD communities?

Chapter 2: Literature Review

HD is a complex condition with a vast constellation of psychological, physical, and social implications. Given the multifaceted nature of the disorder, one can easily get lost in the array of tributaries of investigation there are to follow. Therefore, to navigate the expansive research, this literature review will first address the clinical understanding of the disorder, which will then transition into a more general interpretation of the condition based on the public media's representation of HD, and its impact. Afterwards, the investigation will shift towards current therapeutic intervention strategies and end on societal and cross-cultural considerations. The aim of the following chapter is to present the current research and understanding of the different cohorts of individuals who are involved in this research study. In so doing, an insight to their context will have been represented and their back-stories given a voice, thus allowing for a rich description of experience and themes, which will later emerge within this study.

Clinical Overview of Hoarding Disorder

As with other mental conditions, HD can be found within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which will be the diagnostic tool of focus for this investigation. As an aspiring Canadian psychologist, the *DSM-5* is the main diagnostic tool within the profession and therefore, most relevant to myself, the other professionals I work with, and the clients I aim to serve. As the *DSM-5* is updated to remain abreast to the changes in the field of psychiatry and psychology, two amendments to the latest edition are particularly pertinent to this investigation.

Firstly, in previous editions of the *DSM*, HD was considered a subtype of obsessive-compulsive disorder (OCD), and its diagnostic criteria were not well defined (Mataix-Cols et al., 2011). Now, HD includes a separate diagnosis and set of criteria, which include difficulty

discarding possessions, clutter that interferes with the use of living spaces, and significant distress or impairment caused by the hoarding behaviors (American Psychiatric Association, 2013, p. 251). Additionally, the *DSM-5* no longer requires the presence of compulsions as a necessary criterion for OCD, allowing for the diagnosis of HD even if compulsions are not present (p. 246-252). This differentiation of classification was intended to improve the accuracy of diagnosis and treatment for individuals with HD, and to promote greater understanding and acceptance of the condition (p.251-253)

The second change to the DSM-5 was an increased recognition of the interplay amongst members of varying cultural heritages, and the unique cultural factors that may be at play when diagnosing individuals (Paniagua, 2018). This expanding application of a multicultural lens acknowledges clients' presenting concerns and worldviews intersect with therapeutic processes, which are undeniable considerations within therapeutic interventions (Collins, 2018; Paré, 2013). Moreover, social justice has become increasingly intertwined within the psychological profession, as counsellors are being called to empower clients, both in and out of session, by addressing the intercultural and contextual factors impacting clients, their communities, and society (Collins, 2018). Considering these factors, the shift acknowledges both the condition and the individuals within the multiple systems affected by it. In this way, we can move towards improved client-centered, culturally responsive care.

Classification and Symptomology

In the *DSM-5*, HD is classified as a distinct mental disorder under the category of "Obsessive-Compulsive and Related Disorders" due to the three principal areas of overlap amongst the conditions (American Psychiatric Association, 2013, p. 251). Firstly, both conditions involve repetitive and compulsive behaviors that are difficult to control and often cause distress (p. 237-238). Secondly, individuals with HD often experience intrusive and distressing thoughts related to the need to save or acquire possessions. These obsessive

thoughts contribute to the compulsion to hoard and resemble the thought patterns observed in obsessive compulsive disorder (OCD) (p.239-240). Finally, certain treatments used for OCD, such as cognitive-behavioral therapy and selective serotonin reuptake inhibitors (SSRIs), have also shown effectiveness in addressing symptoms of HD (p. 243). Despite the similarities of the two conditions, the substantial differences in the phenomenology of HD are significant to render a separate categorization. The four main symptomatic expressions of HD are:

1. **Difficulty Discarding Possessions**: A persistent need to save items causes difficulty in parting with personal possessions, regardless of their actual value. This is associated with distress when discarding items occurs (p. 251).

2. **Excessive Accumulation of Items:** Excessive obtaining of objects/items, which leads to cluttered living areas. The accumulation may include items of little to no value or may fill up living spaces to the point where they become unusable (p. 252).

3. **Distress and Impairment:** Social, occupational, and/or other important domains of a person's life become impaired and/or distressed due to hoarding behaviours. For example, the impact can range from isolation to difficulties with daily activities, strained relationships, and/or a compromised quality of life (p.252).

4. Not Attributable to Other Factors: The hoarding behaviors are not better explained by, and or caused by, another mental disorder or medical condition. Moreover, the behaviours and characteristics are ascribed to cultural norms or practices, nor are the struggles in discarding possessions related to a lack of space (p. 253).

Another important means of classification within the DSM-5 relates to the severity of the behaviours, which is based on the degree of functional impairment experienced by the individual, and their level of insight regarding their situation. The severity levels are:

1. Mild**:** The individual shows some s HD symptoms however the impact on functioning is minor. For example, there may only be a slight interference with daily activities with only a mild level of clutter (p. 251).

2. Moderate**:** The symptomatic expressions of HD are more pronounced, with a noticeable impact on daily functioning. The amount of clutter is more significant, and it may start to interfere with the individual's ability to use living spaces effectively (p. 252).

3. Severe**:** The symptoms are severe, which result in significant distress and impairment in multiple areas of life. There is extensive clutter that renders living spaces unusable, and daily activities are severely hampered (p. 253).

Age Considerations

As previously mentioned, the *DSM-5* emphasizes the consideration of psychosocial and cultural variations, which can influence the expression of psychological distress and impact the diagnosis and treatment of conditions (Paniagua, 2018; Smart & Smart, 1997). Unfortunately, the *DSM-5* does not provide the same level of guidance and depth regarding the implications for diagnosing and treating HD across different age groups. Since HD can affect individuals of all ages, it is crucial to differentiate the presentation of HD among different age demographics, as severe symptoms have been reported in senior clients (Ayers et al., 2015; Samuels et al., 2002), and research studies have identified HD behaviors in children and adolescents (Morris et al., 2011; Storch et al., 2011). According to Ayers et al. (2015) and Storch et al. (2011), future publications of the *DSM-5* could be enhanced by adding age-specific criteria, given the unique needs, comorbidity, and experiences associated with HD in these specific age groups. The authors note that by addressing the intersection of generational differences, experiences, and specific needs that may compound the situations of senior and younger HD clients, counsellors can provide holistic and relevant treatment to better support these individuals.

Hoarding in Children and Adolescents Morris et al. (2011) and Storch et al. (2011) point out that there is a scarcity of age-appropriate assessment tools and research for evaluating and understanding HD in young individuals; thus, calling for further advancements in HD pediatric research. Storch and his colleagues outline that applying the current diagnostic criteria for HD with children leads to over-simplified versions of the condition, which may not adequately capture the unique experiences of young individuals. Despite these limitations, both groups of authors indicate that signs of HD can manifest in children aged 10 and under, and that studies have demonstrated that HD symptoms noticed in childhood tend to intensify over an individual's lifetime. Furthermore, Storch and his team mention comorbid conditions accompanying HD in children differ from those observed in adults, with issues such as autism, anorexia, and Prader-Willi syndrome often being present. This can make it challenging for caregivers and clinicians to identify, diagnose, and treat HD in children (Morris et al., 2011; Plimpton et al., 2009; Storch et al., 2011). Additionally, Plimpton et al. (2009), and Storch et al. (2011), point out that since children primarily live within the spaces provided by their caregivers, HD symptoms may be confined to their personal areas, further complicating the detection of problematic behaviors. Moreover, the authors' reports indicate that when caregivers attempt to intervene and declutter these spaces, children may exhibit severe fits and tantrums, leading to parental/child avoidance of the issue, strained interpersonal relationships, and potential rehoming. Morris et al. (2011) furthers the discussion, adding that caregivers of children/minors are often more involved in the therapeutic process than with adults, adopting a supportive and family-based approach can be more beneficial in counselling young individuals with HD. Morris and his team highlights that such an approach allows family members to better understand and manage challenging behaviors while providing support, motivation, and reassurance to HD-affected youth outside of counselling sessions. During counselling sessions, an eclectic treatment approach can be

employed, collaborating with clients and their families, to address comorbid symptoms holistically and cater to their specific needs (Plimpton et al., 2009; Storch et al., 2011).

Hoarding in the Elderly Research has indicated that HD symptoms are three times more prevalent in adults aged 65 and older (Samuels et al., 2002), with reports suggesting a high occurrence of HD in care facilities and personal homes (Ayers et al., 2015). Senior clients face unique challenges in managing HD, including reduced mobility and comorbid health conditions such as arthritis, cognitive limitations, and dementia (Ayers et al., 2015; Sketekee et al., 2001; Tolin et al., 2011). These factors further complicate their situations and contribute to their resistance to change due to low insight and years of habitualized behavior (Ayers et al., 2015; Morris et al., 2011). Additionally, experiences of early childhood trauma, linked to historical events, can further complicate the treatment of HD in this age group (Ayers et al., 2015; Hombali et al., 2019; Thomas, 1997). Negative societal attitudes towards ageism and disability also contribute to the marginalization and lack of social support for senior clients, making it more challenging for them to seek treatment and engage in between-session tasks (Collins, 2018; Ayers et al., 2015). To effectively work with this group, counsellors can utilize case management or task force support to facilitate access to appropriate resources (Allen, 2005; Bratiotis, 2013). Adopting a culturally humble approach, counsellors can better understand the unique intersection of intergenerational experiences, values, and needs, establishing a strong therapeutic alliance with senior HD clients (Ayers et al., 2015; Collins, 2018; Hombali et al., 2019; Thomas, 1997). By considering these factors, counselors can address the complex constellation of issues faced by senior clients with HD, providing equitable access to treatment and employing appropriate strategies to support therapeutic outcomes.

Criticisms of Classifications

Classifications are useful for both the professional members of the mental health field and the clients seeking their services. For example, the *DSM-5* provides professionals across a variety of disciplines have a common language and understanding of the symptoms and conditions that may be affecting an individual, and their varying contexts (Kinghorn, 2014; 10.39). In turn, multiple supportive resources may become more readily available for clients, such as gaining insurance benefits, employment and housing support, medical interventions, etc., (11.43). However, there are limitations and criticisms of the *DSM-5* and its conceptualization of disorders and HD, which are noteworthy.

One general criticism of the *DSM-5,* as voiced by Dr. Allen Frances (2013) relates to the broadening of the number of diagnosable mental disorders, which may lead to an overclassification of behaviours that may otherwise be considered normal (thelensreport, 2013; 1.04). The author mentions the monetary motivations which may be fueling the spike in the number of disorders. In his book *Saving Normal* (2013), Dr. Frances illustrates that, as disorders are often treated with medication, pharmaceutical companies and their related practitioners stand to profit at the expense of over-prescribing unnecessary medication to individuals who are otherwise well. Further, Segal (2019), notes that such expansion in disorders may lead to the misdiagnosis of conditions; particularly those with comorbid conditions and/or which derived out of disorders classified differently in earlier editions of the *DSM*, as is the case with HD (p.497). Therefore, it is advisable that clinicians proceed with the utmost caution when providing an appropriate diagnosis; aiming to carefully consider individual, contextual, and cultural factors (Frances, 2013).

Another criticism of the *DSM-5* is the cultural bias undergirding the diagnostic criteria. Members of the psychological community have noted that the authors of the *DSM-5*

bring their own cultural perspectives and biases when formulating the diagnostic criteria. As mentioned previously, the *DSM-5* has attempted to integrate a more robust consideration of cultural factors and has provided the Cultural Formulation Interview (CFI) (American Psychiatric Association, 2013). Fernández et al., (2018) conducted a cross-cultural, mixed-methods investigation of the CFI across 6-countries, and concluded it be "clinically feasible, acceptable and useful cultural assessment tool." However, Jacob (2014) points out that "the need to elicit patient perspectives, evaluate local reality, assess culture, educate patients about possible interventions, and negotiate a shared plan of management between patient and clinician is cardinal for success." As HD has been noted internationally, it is prudent to consider the application of the diagnostic criteria and use of the CFI with clients.

Clearly, the use of tools such as the *DSM-5* in classifying and approaching disorders such as HD has both benefits and disadvantages. However, as this tool is used by professionals in the mental health field, such nuanced understanding of the condition is not held by the public. Given that clients live within the world, rather than the confines of a manual, it would be prudent to investigate the current perspective of HD held by the members of the community outside of the profession.

Media Depictions and Social Understandings of Hoarding Disorder

The use of popular media to disseminate information and connect people from diverse backgrounds and cultures is not a new phenomenon. With the advent of television and the Internet, popular media has become even more accessible and influential, which has helped to foster greater understanding and connection between individuals and cultures. Authors such as Collins (2018) and Wilber (2000) illustrate how these connections and overlap of shared experiences, historical and financial considerations, socialization, and culture, are the foundation of societal values and an individual's cultural identity. The authors also discuss how this interplay of the inner world of an individual and the shared outer world of the

community affects both parties, as the reciprocal relationship ongoingly shifts and evolves. Therefore, the dynamic between the societal understanding of a mental condition such as HD, and the lived experience of someone with the condition, is connected and complex, with both parties being affected by the other. Though media portrayals may help raise awareness of mental health struggles, the consequences of sensationalizing HD are felt by individual clients, their friends and families, professionals, and the public, long after the show is over.

Individual Impact

The interest and intrigue surrounding the uniquities of HD are evident, as reality shows, such as *A & E's Hoarders* and *TLC's Hoarding: Buried Alive*, have generated record-breaking viewer ratings for over a decade of (Multichannel News Staff, 2018; Furdyk, 2022; Seidman, 2009). Though media portrayals help raise awareness of HD, one may argue that, to boost ratings, the educational factor and human-focused connection is lost, as these shows provide entertainment by sensationalizing the condition and exploiting those affected by the disorder. As a result, the complexities surrounding the epidemiology are oversimplified, leading to false assumptions and negative stereotypes (Bates et al., 2020; Lepselter, 2011; Strong, 2000). According to Corrigan & Watson (2002), the creation and perpetuation of negative stereotypes leads to public stigma. The authors describe this phenomenon to include the concepts of difference, in which people view others unlike themselves, negatives attitudes and distain towards others, and beliefs that an individual is responsible for their situation. Moreover, Reynolds and Placido, (2020) discuss the ways in which Westernized values emphasize free will, thus placing the individual as both the cause of and solution to their issues. Therefore, from an outsider's perspective, HD may be dismissively seen as a personal choice caused by poor cleaning habits, laziness etc., rather than a complex mental illness, which may be onset by trauma and/or accompanied by comorbid conditions (Chasson et al., 2018; Tolin, 2011). Such misunderstandings about the condition may, in turn, decrease

treatment-seeking behavior by those with affected HD, as clients do not wish to be associated with, or discriminated by, the negative labels assigned to the condition (Corrigan & Watson, 2002). This helps to explain the feelings of shame, secrecy and isolation reported by HD clients (Bates et al., 2020; Tolin, 2011), and lead to internalized marginalization within personal and therapeutic relationships (Bates et al., 2020; Corrigan & Watson, 2002).

Family Impact

Research into family members of HD clients show they experience stress, financial burden, negative health implications, and/or social stigma due to their loved ones' condition (Bratiotis & Woody, 2020; Gargiulo et al., 2017; Tolin et al., 2008). Tolin et al., (2008) found family members are compelled to provide support while simultaneously dealing with the invasion of their living spaces by excessive possessions. This situation significantly impairs their quality of life, limiting their access to basic amenities like washing, cooking, and even sleeping (p. 12). Furthermore, the authors discovered that children living in these circumstances reported elevated levels of embarrassment and social withdraw. Chabaud (2011) has found that younger children of individuals with HD often feel confused and powerless to change their situations, less important to the items in the home, physically endangered and emotionally neglected. The author notes that as these children become adults, if their parents continue to neglect their issues and resist treatment, relationships are strained and broken.

Additional investigations have also revealed animosity between hoarding family members and their relatives intensifies, leading to family disintegration as the strain becomes unbearable (Tolin et al., 2008; Wilbram et. al., 2008). In such circumstances, some individuals with HD are left to confront their problems alone. As HD is characterized by a limited insight into the severity of the condition (American Psychiatric Association, 2013), the true degree of understanding regarding personal safety, health risks, and the possibility of

legal consequences, renders people with HD increasingly vulnerable. This vulnerability amplifies the distress experienced by family members. Büscher et al. (2014) note that even when physically distanced from the hoarding environment, family members struggle to sever their emotional ties with their loved one (p. 494). In many instances, the family members and individuals with HD lack understanding of the condition, which further exacerbates the rejection felt towards hoarding family members and deepens their sense of isolation, defeat, and loneliness (p. 496). Despite the bleak outlook, there are instances that contradict this narrative, revealing glimpses of hope within families. These cases demonstrate the potential to overcome the problems and conflicts arising from hoarding behavior and build strong, supportive familial relationships. Sometimes, this progress is achieved from the inherent strength of familial bonds, while in other instances, it stems from the guidance of experts (p. 496).

Professional Impact

As previously mentioned, Westernized treatment practices place clients at the center of a disorder, view them as those in need of remedy (Dickerson & Zimmerman, 1995), and assumed to have the free will to do so (Reynolds & Placido, 2020). This method prescribes a one-directional approach to counselling, with the expert therapist providing insight and the knowledge to cure clients of their problems (Dickerson & Zimmerman, 1995). This is supported by the ways therapists and therapy are portrayed on reality shows, as per their quick interventions, which do not focus on long-term growth and change (Jamieson, 2011). Whilst one may argue that this is due to the time restrictions of a television program, the negative consequences of bias towards HD clients have been documented. Holden, et al. (2019) found that therapists working with HD clients report prominent levels of hopelessness and frustration, which leads to an overall diminishing of the therapeutic alliance (TA). As the TA has been considered as one of the key ingredients in counselling to achieving positive

treatment outcomes (Laska & Wampold, 2014), the negative repercussions in this regard are concerning. The factors contributing to therapists' frustrations include clients' low insight and low adherence to between-session activities, and therapists' feelings of client rejection (Holden, et al., 2019; Tolin et al., 2012). Therefore, it would appear the that same issues that HD clients experience with respect to low insight, motivation, and readiness to change (Frost et al., 2010, Tolin, 2011), are undergirding therapists' frustrations (Tolin et al., 2012). This may indicate clients' needs and position within the therapeutic process are being placed behind therapists' expectations and bias (Collins, 2018; Vasquez, 2007), and/or a lack of responsivity for clients' preferences and applied treatment modalities (Collins, 2018; Xu & Tracey, 2016). Furthermore, research indicates that HD clients are often terminated or referred, without much opportunity to build or repair the TA and achieve treatment outcomes, thus diminishing clients' motivation to continue seeking treatment (Tolin et al., 2012).

Though current research does not contain evidence of client feedback in HD treatment processes, integrating practice-based evidence can be useful to ensure therapeutic processes are congruent with clients' expectations and needs, to customize treatment (Paré & Sutherland, 2016). In addition, ongoing training, and supervision for counsellors to improve their understanding of the condition through professional support can be beneficial to ease counsellor tensions and improve their work with HD clients (Tolin et al., 2012). One criticism of these suggestions is that continuous training and supervision within the therapeutic practice, and the inclusion of practice-based evidence, may be costly and time consuming (Collins, 2018). However, ensuring ongoing collaboration between the client and counsellor to ensure best practice (Paré & Sutherland, 2016), whilst professionally addressing counsellors' concerns, can strengthen client and counsellor roles within the TA; further supporting clients' achieving treatment outcomes (Tolin et al., 2012; Vasquez, 2007). As understanding the dynamic of the TA is extremely important, is it equally necessary to

consider the treatment approaches and strategies that are currently being used with HD clients; as unique clients require unique interventions to best suit their needs.

Current Treatment Modalities of Hoarding Disorder

According to Dickerson and Zimmerman (1995), and Truscott (2010), treatment approaches stem from theoretical frameworks, which are rooted in assumptions that shape our understanding of human cognition, emotions, and behavior. Mertens (2020) furthers the discussion by adding that traditional psychological perspectives, influenced by modernist assumptions, tend to view clients and their experiences as objectively describable, measurable, and definable truths. Consequently, the authors note that conventional treatment modalities primarily target the symptoms deemed maladaptive or problematic based on expert or societal judgments. Whilst the writes point out that postmodernists and social constructivists have embraced multiple possibilities and recognize the influence of sociocultural contexts on individuals' worldviews, Collins (2018) adds that the focus on symptomology persists. She mentions that this often overlooks the clients' unique perspectives and cultural backgrounds in the development and implementation of therapeutic models. Soto et al. (2018) furthers the discussing, noting that enhancing cultural responsiveness and treatment outcomes in therapy requires adapting treatment modalities, exploring alternatives that align with clients' individual needs and circumstances, and integrating their values into the therapeutic process. To expand on this, we will investigate the most used treatment therapy for HD, briefly discuss integrative treatment, and consider alternative therapies.

Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) draws from constructivist approaches pioneered

by Albert Ellis and Aaron T. Beck, emphasizing the influence of cognition on behavior and the potential for behavior change through cognitive monitoring and adjustment (Beal, 2019; Mertens, 2020; Truscott, 2010). Additionally, it recognizes that individuals' perceptions, rather than external circumstances, shape their interpretation of events, and modifying these interpretations can lead to positive or negative outcomes (Beal, 2019; Truscott, 2010).

CBT has been extensively utilized in the treatment of HD, targeting symptoms such as distorted beliefs about possessions, information processing challenges, and decision-making difficulties that may impede progress in therapy (Frost & Hartl, 1996; Frost et al., 2010; Kyrios et al., 2017; O'Connor et al., 2017). Its empirical support has positioned CBT as the gold standard treatment for HD, making it the most employed approach (Kyrios et al., 2017; Murphy, 2014; Steketee et al., 2010). However, research on CBT's effectiveness reveals high dropout rates, low treatment adherence, and a considerable number of clients who continue to experience symptoms following CBT interventions (Chou et al., 2020; Tolin, 2011). Given that CBT does not adequately address many co-occurring conditions associated with HD, such as self-ambivalence, avoidance, and trauma, which are undoubtedly impacted by cultural factors, there is a need to integrate alternative treatment modalities to address these unmet aspects (Chou et al., 2020; Collins, 2018; Tolin, 2011).

Integrative Treatment Modalities

Integrated approaches to counselling involve combining various treatment modalities to address clients' presenting concerns and align with their preferred therapeutic interventions, without adhering to a specific theoretical framework (Howard et al., 1986; Truscott, 2011). Drawing on Lazarus' Multimodal Behavior Therapy Model and Beutler's Eclectic Psychotherapy Model, which are rooted in the pragmatic paradigm (Mertens, 2020; Truscott, 2011), integrative-eclectic counseling emphasizes flexibility in matching clients' therapeutic preferences with the counselor's treatment orientation, aiming to achieve the most

suitable therapeutic practices (Howard et al., 1986; Truscott, 2011). While it has been criticized for its complexity in application, as counsellors still require theoretical frameworks to guide their choice of treatment modality for clients (Howard et al., 1986; Petrocelli, 2002; Truscott, 2011), utilizing eclectic treatment models can enhance therapeutic outcomes by integrating clients' level of insight, motivation, and pace throughout the therapeutic process (Petrocelli, 2002; Prochaska et al., 1992).

Culturally Responsive Counselling

According to authors Collins (2018) and Paré (2013), culturally responsive counselling recognizes clients as unique and intricate individuals, whose lived experiences and worldviews are pertinent to their concerns. The writers posit that rather than viewing clients solely through the lens of symptoms requiring a cure, it is crucial to integrate their experiences into a personalized therapeutic journey. Employing an anti-pathologizing perspective allows for collaborative case conceptualization, where contextual factors are considered, and clients' perspectives on health and healing take precedence. Smith (2016) supports this position, noting this approach facilitates the establishment of culturally responsive counselling goals and change processes that are relevant and tailored to the individual. While there is currently no research specifically exploring multicultural approaches to HD, existing literature indicates that clients' perception of the therapist's willingness to understand their cultural identities significantly contributes to their satisfaction with counselling (Chang & Yoon, 2011; Constantine, 2002; Fraga et al., 2004; Sanchez, 2020). Moreover, adapting treatment to incorporate cultural aspects has shown a positive correlation with treatment outcomes (Flynn et al., 2020; Gonzalez et al., 2018; Soto et al., 2018). Although further investigation is necessary in this field, the incorporation of multicultural counselling strategies in the treatment of HD can be beneficial in achieving

positive treatment outcomes.

Transtheoretical Model

According to Prochaska et al. (1992), The development of the Transtheoretical Model (TTM) was driven by challenges observed in addiction counselling, where clients frequently lack insight into their situation and motivation to change. Frost et al. (2010) adds that these challenges can impede clients' engagement in therapy and result in less favorable treatment outcomes and is often the case with HD clients. TTM can be employed alongside other strategies to address change in a developmental manner. Petrocelli (2002) extends the discussion, noting the counsellor's role is to facilitate insight, motivation, and readiness to change at the client's own pace, adapting to various stages of treatment. Moreover, TTM recognizes that setbacks and regression are part of the learning process and can help alleviate feelings of failure while maintaining motivation (Hashemzadeh et al., 2019; Reynolds & Placido, 2020). Although TTM has faced criticism regarding the reliability of stage assessment tools, the potential oversimplification of change processes within a stage-based model, and assumptions of clients' free will to change (Armitage, 2009; Brug et al., 2005; Reynolds & Placido, 2020), it offers valuable elements that contribute to treatment outcomes and has empirical support (Armitage, 2009; Prochaska et al., 1992). By recognizing and addressing factors that impede progress, pragmatic and integrative modalities can enhance treatment effectiveness by providing a customized approach to therapeutic change strategies (Prochaska et al., 1992; Reynolds & Placido, 2020). While there is currently no research specifically examining TTM in the context of HD, given the shared characteristics between HD and substance-use clients (Frost et al., 2010; Petrocelli, 2002) and the positive impact of TTM in substance-use treatment (Prochaska et al., 1992; Hashemzadeh et al., 2019), incorporating TTM as a framework, along with other strategies, can be beneficial in supporting HD clients throughout their therapeutic journey. As clients' successes impact their

interpersonal relationships and therefore communities, understanding HD clients'

surrounding contexts is a critical consideration for our investigation.

Societal Considerations

HD distinguishes itself from other conditions by its wide-ranging social impact.

Studies by Bratiotis and Woody (2020) and Gargiulo et al. (2017) have shown that HD

behaviours lead to the health and safety of cohabitants, neighbors, and the broader

community through unhygienic conditions and the risk of fire. Cramer and Vols (2016) and

Frost et al. (2000) add that, given the significant governmental resources allocated to support

the individual and social implications of HD, the disorder has been acknowledged as a

community health issue.

One way HD presents socially are through the various legal issues which may be

associated with the condition. Specifically, the authors note that issues involving property

owners, city officials, health workers, and other entities frequently arise for HD clients.

Consequently, Frost et al. (2010) notes that clients may be compelled and/or made to seek

counselling to address their living conditions and avoid eviction or legal repercussions. It has

been observed that mandated time limits and forced interventions do not yield positive

treatment outcomes for HD clients, as living conditions tend to revert to their previous state

quickly (Akhtar, 2019; Bratiotis & Woody, 2020). Given that shame, secrecy, and social

isolation are inherent aspects of HD (Tolin, 2011; Frost et al., 2010), public exposure and

external impositions can intensify feelings of shame and trigger defensiveness during

treatment (Frost et al., 2010). If HD is indeed considered a social health concern (Frost et al.,

2000), it necessitates the implementation of social justice measures to protect HD clients

from unfair discrimination and ensure equitable treatment (Collins, 2018) in legal situations.

Power Relations

In the context of forced treatment and legal requirements, Frost et al. (2010) notes that individuals with HD often experience power struggles when faced with judges, property owners, or other authority figures demanding action. Tolin (2011) adds to the discussion, mentioning that due to their limited insight into their condition, HD clients may perceive forced treatment as an infringement upon their autonomy and the right to live according to their chosen lifestyle. Consequently, as per Laska and Wampold (2014), clients may enter counseling with preconceived notions and negative expectations, which can detrimentally impact treatment outcomes. Along with Frost et a. (2010), the authors note that the counsellor, seen as an authority figure, may also be perceived as imposing beliefs and requirements on the client, thus hindering the establishment of a therapeutic alliance (TA) and impeding the treatment process. Additionally, the authors elucidate that clients' resistance to treatment may be heightened, leading to defensive responses during sessions and impeding progress.

Addressing power struggles at the outset of intervention is essential to foster rapport and establish a TA (Frost et al., 2010). Motivational Interviewing (MI), a constructivist approach to counselling (Mertens, 2020), has proven effective in addressing power relations when working with defensive HD clients (Frost et al., 2010). According to Foiland (2020) and Rollnick and Allison (2004), MI combines Rogerian non-confrontational dialogue with psychosocial models that perceive motivation as a changeable, contextually based phenomenon. The authors, along with Frost et al. (2010) illustrate that by exploring clients' perceived discrepancies between their current situation and their desired goals, and involving key stakeholders in the change process, MI helps enhance clients' motivation to engage in counselling while maintaining a balanced approach to hierarchical relationships.

Social justice principles also call upon counsellors to utilize their professional position to advocate for change beyond the counseling session, promoting positive systemic change at

the meso and macro levels (Collins, 2018). While progress has been made in terms of community-based teams and counsellors supporting social support for HD (Kwok et al., 2017), counsellors can further promote social justice at the civil and judicial levels. According to Cramer and Vols (2016), this includes educating decision-makers and collaborating in legal cases to provide more client-specific courses of action, such as realistic periods for compliance, when dealing with individual HD clients. The authors note that counsellors can also ensure that clients are informed about and granted access to support systems, such as alternative housing or clean-up services, which they are entitled to by law within their specific district during the legal decision-making process. As per Collins (2018), these efforts help rebalance power differentials between authority figures and HD clients, ensuring that clients' perspectives, needs, and voices are heard by decision-makers before determining appropriate courses of action.

Community Involvement

Given the intricate nature of HD, particularly when it affects the broader community, the involvement of multiple service providers such as fire officials and clean-up workers become necessary at various stages of intervention (Bratiotis et al., 2019; Kwok et al., 2017). According to Bratiotis et al. (2019), coordinating these resources often exceeds the client's capabilities, highlighting the need for coordination efforts on their behalf. Mertens (2020), adds that case management (CM), which encompasses aspects of both the transformative and pragmatic paradigms, empowers marginalized clients by facilitating access to appropriate health and service providers based on their individual needs. Despite criticism regarding its perceived slowness and limited funding, CM has proven to be a valuable approach in assisting HD clients (Bratiotis et al., 2019).

Allen (2005) notes that an alternative to CM involves the formation of specialized groups, known as task forces, where multidisciplinary community stakeholders collaborate to

address social challenges. Bratiotis (2013) adds that these task forces involve public and governmental agencies sharing responsibility for required tasks, leading to efficient service provision while accommodating and distributing costs. Tolin et al. (2013) furthers the discussion, mentioning that to mitigate potential power struggles and enhance working alliances during interventions, individuals who may not be seen as authority figures, such as family members, community members, or personal organizers, can play a significant role. The authors do note that task forces, however, have been criticized for the potential lack of ongoing commitment by agency members and the scarcity of longitudinal research. Nevertheless, the research mention that adopting a collective, community-based response to HD can shift the responsibility for treatment away from clients, resulting in positive changes for both HD clients and community members. This may be furthered by understanding and integrating cultural factors at the individual and community level.

Cultural and Cross-Cultural Considerations

According to the American Psychiatric Association (2013), and Paniagua (2018), the *DSM-5* emphasizes the significance of cultural factors, including socioeconomic and psychosocial circumstances, that can influence clients' presenting issues. Smart and Smart (1997) add that the *DSM-5* distinguishes these factors from culture-bound syndromes, which are culturally specific manifestations of distress that impact clients' mental health. Therefore, according to the authors, it is essential for practitioners to avoid underestimating or overgeneralizing these factors when diagnosing and treating multicultural clients. While cross-cultural research has indicated the presence of HD in many countries and the universality of certain client characteristics (Kuwano et al., 2020; Timpano et al., 2013; Zartaloudi, 2020), the majority of HD research has been conducted in individualistic, Western countries with Caucasian participants (Dwivedi, 2020; Fernández de la Cruz et al., 2016; Timpano et al., 2013). This limited focus fails to address the diverse sociocultural

perspectives and contextual factors that can influence clients' diagnoses, therapeutic

processes, and treatment outcomes (An & McDermott, 2014; Fernández de la Cruz et al.,

2016; Yang et al., 2018). By integrating cultural contextual factors into therapeutic processes,

both clients and counselors can better identify culturally relevant causes and treatment

strategies for HD, addressing the intersectionality of clients' worldviews and presenting

concerns.

External Contributions of Hoarding Disorder

As noted earlier, the concept of free will is deeply rooted in Western beliefs and many

traditional psychological frameworks, placing responsibility on the client for their condition

and its resolution (Bratiotis & Woody, 2020; Reynolds & Placido, 2020). However, adopting

a culturally responsive perspective shifts the focus away from individual control and

responsibility, considering historical and societal factors that can influence the development

and persistence of psychological issues (Collins, 2018).

Research indicates that HD tendencies may stem from evolutionary behaviors

(Akhtar, 2019), genetic vulnerability (Alonso et al., 2008; Hombali et al., 2019), traumatic

historical events like the Great Depression (Hombali et al., 2019; Thomas, 1997), and cultural

values surrounding cleanliness and social status (Akhtar, 2019; Bates et al., 2020; Shove,

2003). These dominant cultural values have contributed to public stigmatization and negative

attitudes towards individuals with HD (Akhtar, 2019; Bates et al., 2020). Counsellors, as

agents of cultural responsivity, can address HD at the micro, meso, and macro levels of

systems (Collins, 2018). Raising awareness of the external factors contributing to HD among

clients, their families, and communities can promote greater understanding and reduce stigma

(Bates et al., 2020). Additionally, counsellors can use their professional positions to advocate

for improved media representations of HD clients, highlighting their strengths and abilities

rather than sensationalizing their behaviors and shortcomings (Collins, 2018; Bates et al.,

2020). Through education and advocacy, counsellors and community members can challenge

the existing narratives, recognizing dominant discourses as products of oppressive systems

rather than moral failings of those affected by HD (Bates et al., 2020; Corrigan & Watson,

2002).

Collectivism and Hoarding Disorder

As many traditional approaches to psychology are founded in Western, individualistic

values (Dwivedi, 2020; Truscott, 2011), the undergirding understanding of individuals and

their contexts varies with those of collectivistic cultures (Breckenridge, 2019; Dwivedi,

2020). According to Breckenridge (2019), collectivism values include community

involvement and cooperation, strong family-orientation, and face-saving systems of behavior.

An and McDermott (2014) add that these values have negatively impacted social stigma

surrounding mental illness, inhibiting individuals from directly seeking support from

community members and/or health workers. As Western-based research has revealed shame

and guilt to be highly associated with HD (Frost et al., 2010; Tolin, 2011), these

characteristics may be exacerbated in collectivistic cultures (An & McDermott, 2014).

According to Kuwano et al. (2020) and Timpano et al. (2015), these cultural discrepancies

may account for the significantly lower reporting of HD prevalence in East-Asian studies.

Furthermore, the authors note that Eastern cultural attitudes towards wastefulness and

cherishing personal possessions may further affect clients' insight and reporting of HD in

these contexts.

In addition, cultural disparities in the use of Western generated assessment tools may

further complicate HD reporting and research, such as issues of cultural interpretations of

items (Mertens, 2020; Timpano et al., 2015), the tendency to only report extreme values on

Likert scales (Timpano et al., 2015), and accuracy of translations (Fernández de la Cruz et al.,

2016; Mertens, 2020; Timpano et al., 2015), with multicultural clients. Cultural discrepancies

for therapeutic approaches must also be considered, as members of collectivistic cultures prefer indirect, discreet methods of seeking treatment and discussing presenting concerns (An & McDermott, 2014). According to Xu and Tracey (2016), in this light, CBT may be seen as confrontational and therefore, not as effective. A study, presented by the authors, recommends alternative approaches to HD treatment, such as Indigenous and Humanistic approaches, as they are more culturally congruent with collectivistic views on health and healing. Though the development of more culturally appropriate assessment tools, and the training of Western counsellors to multicultural clients' values and treatment preferences, may be costly and time consuming (Collins, 2018; Mertens, 2020), ensuring culturally congruent means of reaching clients, conducting research, and counselling practices (Fernández de la Cruz et al., 2016; Timpano et al., 2015; Mertens, 2020; Xu & Tracey, 2016), can provide a more accurate understanding of the international scope and phenomenology of HD, while resulting in more effective treatment practices of HD for clients, worldwide.

Conclusion

HD is a phenomenon that has far-reaching effects on various levels of society and the global community. While considerable progress has been made in terms of its classification in the DSM-5 (American Psychiatric Association, 2013) and research efforts to comprehend its etiology and phenomenology, there remains a substantial amount to consider in understanding HD and implementing effective treatment approaches for individuals experiencing this condition. The case conceptualization of HD clients presents challenges due to the intricate interplay of cultural identity, values, worldviews, personal and historical experiences, societal factors, cultural variations, age-related considerations, and individual needs and preferences (Collins, 2018; Paré, 2013) that surround HD clients.

Given the multitude of factors to consider, it is understandable that many counsellors may feel overwhelmed by the demands of working with HD clients (Holden et al., 2019).

However, it is crucial for us, as counselors, to recognize that the challenges and uncertainties faced by individuals affected by HD daily are even more daunting. By approaching HD clients with empathy, viewing them as unique and diverse individuals through a non-judgmental and anti-pathologizing lens (Collins, 2018; Paré, 2013), and providing integrative and collaborative, community-based treatment, we can collectively strive toward best practices in HD. Taking this empathetic and inclusive approach as an international community of practitioners can bring us closer to understanding the complexity of HD and facilitating effective interventions that meet the diverse needs of individuals impacted by this condition.

Chapter 3: Theoretical Framework

After delving into the extensive literature surrounding HD in the preceding chapter, this section aims to provide a comprehensive overview of the theoretical framework which undergirds the projects. Afterwards, the unique framework, as outlined by Ken Wilbur's (1995) All Quadrants All Systems (AQALS) framework will be illustrated, thus providing the backdrop and premise of this project. From there, the unique research approach adopted, digital ethnography, which offers valuable first-person insights into the intricate dynamics of HD, will be defined, and explored.

Theoretical Foundation

This research project relies on the distinct comprehension and personal involvement of individuals in understanding HD. According to Mertens (2020), employing subjective descriptions from each person's perspective aligns with the constructivist paradigm, which asserts that reality exists in diverse forms. Creswell and Poth (2018) add that constructivism adopts a subjective and interactive approach to investigate phenomena, acknowledging the interplay between researchers and participants in co-constructing the meaning of experiences. The authors emphasize that this approach allows researchers to interpret actions, behaviors, and contextual/cultural factors, considering contradictions as a starting point for attaining fresh insights. Moreover, the writers recognize that constructivists appreciate the existence of multiple realities and recognize that a complex phenomenon can be perceived and explained in many ways, thus aiming to preserve and present each perspective.

As evident from the literature review, HD is a condition that impacts individuals across various countries and diverse cultural backgrounds. While the constructivist paradigm acknowledges multiple realities and considers contextual and cultural factors, I believe that incorporating a theoretical framework encompassing diverse worldviews will enhance the

project, which is why Ken Wilber's (1995) Integral Theoretical framework has been
employed, which I will elaborate on.

All Quadrants All Levels

The Integral Theoretical All Quadrants All Levels (AQALS) framework, developed
by philosopher Ken Wilber (1995), integrates Eastern and Western philosophies to provide a
more holistic understanding of human thinking and behavior. As illustrated in Figure 1,
Wilber's matrix encompasses two conditions: (1) interior or exterior, and (2) singular or
plural, with the left-hand quadrants representing the interior state and the right-hand
quadrants representing the exterior state. Additionally, the upper quadrants differ from the
lower ones based on singular or plural characteristics.

Figure **1**

The Four Quadrants of the AQALs Model, Wilber, 1995
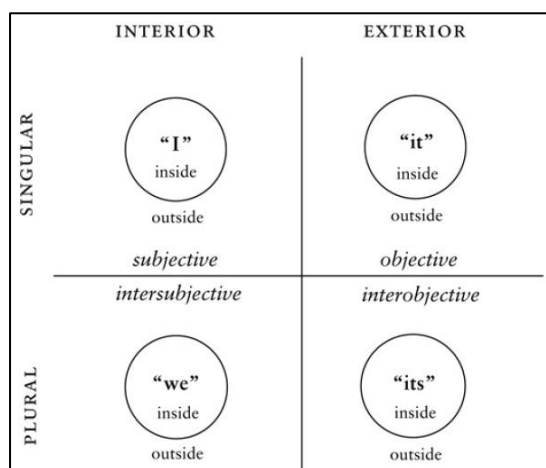
Individually, the four quadrants can be better understood as the following:

1. **Individual Interior (I)**: This quadrant focuses on the subjective, individual, and
   internal experiences of a person.

Examples include: a) Personal thoughts and beliefs; b) Emotions and feelings; c)
Introspection and self-awareness

2. **Individual Exterior (It)**: This quadrant deals with the objective, observable, and external aspects of an individual.

Examples include a) Physical body and its actions; b) Observable behaviors and actions, and; c) Brain activity and neural processes

3. **Collective Interior (We)**: This quadrant addresses the shared, subjective, and collective experiences within a group or society.

Examples include a) Shared cultural beliefs and values; b) Collective emotions and social norms and; c) Group identity and sense of belonging

4. **Collective Exterior (Its)**: This quadrant involves the observable, external, and systemic aspects of a collective entity.

Examples include a) Social structures and institutions; b) Economic systems and policies; and; c) Environmental and ecological systems

By utilizing this framework in the study, I can interpret and contextualize the multiple perspectives shared by the participants, taking cross-cultural considerations into account. Since this approach to HD research is not currently prevalent in the literature, this study can establish a foundation for future projects that incorporate the insights and experiences of individuals living with the condition. Having explored the undergirding theoretical foundations of this project, I will now elucidate on the methodological approached used to conduct this project.

Digital Ethnography

According to Creswell and Poth (2018), ethnography originated in the field of anthropology, where researchers employed strategies derived from the natural sciences to observe and comprehend diverse cultures. The authors note that over time, these methods were adopted and adapted by sociologists and psychologists to gain insights into subcultures within broader societies. Van Maaden (2011) adds that ethnography seeks to bridge the gap

between the outsider (i.e., the ethnographer and readers) and the intricate world of insiders (i.e., members of a specific culture or subculture, who may also be readers), aiming to develop a unique understanding of the culture that influences social discourses and group dynamics.

With the advent of technology and the emergence of social media platforms such as Facebook, which connect individuals and facilitate the formation of interest-based groups, Digital Ethnography (DE) refers to researchers applying ethnographic principles and methods to settings of computer-mediated communication (CMC) (Androutsopoulos, 2008). While DE builds upon traditional ethnography, it is important to explore the underlying principles of both methodologies to better grasp the distinct principles of DE.

Principles of Digital Ethnography

Creswell and Poth (2018) outline six key principles that are commonly observed across various disciplines and applications of ethnography:

1. Ethnographic research focuses on studying a well-established culture-sharing group characterized by distinct social patterns, language, and other defining features.

2. Ethnographers aim to identify and comprehend patterns of behavior, thoughts/beliefs, and interactions that illustrate the group's social organization, worldviews, and inter-group systems.

3. Ethnography is influenced by the researcher's theoretical background, which shapes the aspects of the group under investigation and subsequently informs the understanding and interpretations made.

4. Ethnographers often engage in extensive fieldwork, employing a range of data collection strategies such as interviews, observations, and the collection/interpretation of group-specific artifacts.

5. Data analysis in ethnography involves a combination of the insider's emic perspective, conveyed through direct quotations, and the ethnographer's etic/outsider's perspective. This approach contributes to an informed cultural understanding of the research findings.

6. The outcome of an ethnographic investigation reveals the social functioning and infrastructure of a specific group, as well as the processes through which newcomers can assimilate into that group.

Building upon the foundational principles, Pink et al. (2015) identifies five distinctive principles of Digital Ethnography (DE):

1. Multiplicity: The digital landscape, including access, availability, and variety, is shaped by the unique infrastructure of specific locations and contexts. DE is influenced by factors such as Internet speed, access limitations, and available technological infrastructure at individual and societal levels.

2. Non-digital-centric-ness: DE recognizes that technology and digital interactions exist within a broader context that encompasses offline relationships, experiences, and environments. Understanding the digital realm requires considering its interconnectedness with the physical world.

3. Openness: DE is not confined to a rigid research method with defined boundaries; instead, it is an open-sourced process. Openness in DE involves embracing diverse creative digital sharing and collaborative methods that serve as the foundation for being and relating to others in digitally mediated spaces.

4. Reflexivity: DE investigates and reflects on the ways in which knowledge is constructed, theorized, and encountered through a digital-material-sensory lens. This reflexive approach helps researchers gain a deeper understanding of the specific ways of knowing and being within digitally based communities.

5. Unorthodox: Digital groups consist of members from various cultures and demographics, each with distinct levels of online and computer competencies. Communication methods within these groups may involve unconventional elements such as emojis and pictures. Researchers conducting DE should be open to depart from traditional language and discourse-based analysis, allowing for unorthodox representations of individual and group membership and expression throughout the research design, data collection and analysis, and interpretations.

Like other qualitative methodologies, DE is influenced by philosophical underpinnings that align with the methodology's principles and the researcher's position. These philosophical foundations play a crucial role in shaping the ontological (the nature of reality) and epistemological (the nature of knowledge) understanding, as well as the overall research direction of a particular investigation (Creswell & Poth, 2018).

Philosophical Underpinnings

DE research seeks a rich understanding of social groups, often adopting a constructionist perspective (Creswell & Poth, 2018; Pink et al., 2015). Constructivism recognizes that meaning and understanding emerge from engagement with one's contextual realities (Rashid et al., 2016; Van Maaden, 2011). This perspective acknowledges the collective transmission and generation of meaning and the influence of cultural contexts on our perceptions (Crotty, 1998). Socio-cultural theory further emphasizes the impact of social sources on individual perspectives and worldviews (Wertsch, 1991). DE aligns with these notions, as researchers immerse themselves in socially constructed understandings to co-construct meaning at individual and collective levels (Rashid et al., 2016; Pink et al., 2015; Van Maaden, 2011). DE is appropriate for my research as it is an unobtrusive way of gaining the insiders' perspectives and experiences in HD. Moreover, with the developments of COVID-19, it is my assumption that more individuals have turned to online support groups to

connect with others. Therefore, to stay current with people's experiences within our modern

landscape, DE can help us to gain insider perspective to elaborate on what is helpful for those

facing HD. This is also congruent with the Integral Theoretical framework previously

mentioned, as it acknowledges the inner and outer contexts surrounding the individuals of the

study. In as much as the philosophical underpinnings of DE and their applications are

influenced by the position of the researcher, the method itself may be situated in several

ways.

Methodological Situation

DE research can be situated in many ways depending on its aims. According to

Creswell and Poth (2018), there are two main forms emphasized: realist ethnography (RE)

and critical ethnography (CE). In RE, the researcher maintains an objective perspective,

avoiding the inclusion of personal and political values in the final write-up (Creswell & Poth,

2018; Van Maanen, 2011). This approach outlines group intricacies using culturally

descriptive categories and paraphrased renditions of participants' responses, presenting the

findings through the lens of the ethnographer (Creswell & Poth, 2018; Van Maanen, 2011).

RE aligns with objectivism, considering understanding and values as independent of both the

individuals under study and the researcher (Rashid et al., 2016). It also fits within the post-

positivist paradigm, with the researcher adopting an objective role and reporting findings

without judgment (Creswell & Poth, 2018; Mertens, 2020).

In contrast, CE incorporates the direct and subjective voices of participants and the

researcher, constructing knowledge through close interactions and insider/outsider

relationships (Creswell & Poth, 2018; Fetterman, 2010; Mertens, 2020). According to

Creswell and Poth (2018) and Fetterman (2018), the final presentation in CE provides a

comprehensive understanding of the group, including their worldviews and cultural identities.

Moreover, the authors note CE can be used to advocate for marginalized groups by

amplifying their voices and challenging the status quo. CE aligns with constructivism, socio-cultural theory, and interpretivism, recognizing the co-construction of understanding through relational experiences between the researcher and participants, acknowledging the interplay of culture and the individual in shaping meaning (Rashid et al., 2016; Fetterman, 2010; Pink et al., 2015). Personally, I lean towards CE due to its philosophical underpinnings and the potential for research to align with my worldviews and values.

Role of the Researcher

In RE, the researcher takes on a passive observer role, aiming to report findings in a neutral manner (Creswell & Poth, 2018; Van Maanen, 2011). Creswell and Poth (2018) and Mertens (2020) note that while complete neutrality may be challenging to attain due to inherent biases, the realist ethnographer strives to minimize personal influence. In my study, I have adopted an objective stance, as per the authors' description; refraining from direct interaction with participants and presenting findings without judgment. As an outsider to HD with no personal connections or experiences, I acknowledge my position as a true outsider. However, having been exposed to popular media portrayals of HD, I am aware of potential personal reflections and biases that might impact my interpretation of participants' descriptions. To address this, I have employed bracketing techniques, as suggested by Mertens (2020), such as reflective journaling, and maintain ongoing discussions with professional colleagues, to identify and address any assumptions or potential interference related to the topic. However, it is prudent to acknowledge that DE presents unique challenges that ethnographers must creatively overcome.

Challenges of Digital Ethnography

DE offers several advantages, including invisible/unobtrusive observation of CMC groups, access to history logs to gather (retroactive) longitudinal data, and an array of data-gathering opportunities (Androutsopoulos, 2008; Varis, 2015). However, DE does include

unique concerns, including contextual issues, the researcher's role, and consent/ confidentiality considerations.

Ethnographers traditionally focused on a specific group in a particular location with members sharing a homogeneous culture or association (Van Maaden, 2011). This approach allowed for localized and specific context, enabling researchers to gain insights into the group's intricacies as expressed by its members. However, advancements in technology have facilitated the formation of international groups, leading to significant variations in language, culture, understanding, and context among members (Darvin, 2016; Varis, 2015). Digital material can be easily replicated, mobilized, and recontextualized, causing the meanings and functions of interactions among members to evolve beyond the original focus context (Gerogakopoulou, 2013; Rymes, 2012; Varis, 2015). Additionally, with widespread access to the internet through mobile devices, the boundaries between offline and online worlds have become increasingly blurred (Varis, 2015). Furthermore, interactions among group members may occur in invisible contexts, such as private messages, impacting the researcher's understanding of group dynamics (van Dijck, 2013; Varis, 2015). The contexts in DE are complex and multifaceted, requiring innovative approaches to address these concerns. Existing literature suggests that researchers should consider micro-level factors, such as participants' demographics, interaction patterns within the group, and their engagement with the platform, by conducting interviews alongside observations (Gerogakopoulou, 2013; Rymes, 2012; Varis, 2015).

In DE, researchers can engage with participants through various forms and in multiple contexts, including online/offline semi/structured interviews, silent observations, and participation as a member. Hine (1998) proposes that participating in one online community while also being a part of a separate, but similar, group offers a unique perspective and dimension that would otherwise be unattainable. Furthermore, data from these multiple

sources can be triangulated to enhance the research's validity and reliability (Bow, 2000; Mertens, 2020). However, ethical concerns may arise regarding researchers posing as participants or lurking within groups (Jones, 1997; Varis, 2015). To address these concerns, the Tri-Council Policy Statement (TCPS 2) by the Canadian Institute of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada emphasizes the importance of researchers identifying themselves and their intentions to group gatekeepers/administrators when seeking admission (TCPS 2, 2018, p. 138).

Privacy and confidentiality are particularly critical in DE due to the ease with which individuals' usernames, information, and quotes can be searched and identified (TCPS 2, 2018; Varis, 2015). Depending on the research context and the researcher's level of involvement, preserving participants' privacy becomes challenging when using their exact quotes. In such cases, researchers must obtain informed consent throughout the study, paraphrase participants' quotes, or modify usernames to protect their identities (TCPS 2, 2018; Varis, 2015). Having explored the key principles, philosophical underpinnings, and concerns associated with DE, the discussion will now focus on illustrating the use of DE in the current investigation. This will include explaining the rationale for choosing DE, describing the sample, outlining the handling and data analysis procedures, and addressing ethical concerns.

Chapter 4: Methods

Having explored the theoretical framework in the preceding chapter, this section aims to provide a comprehensive overview of the methodological approach employed in this study. This will be achieved by exploring the rationale for utilizing Digital Ethnography (DE) and the sample selection. This will segway into the ethical considerations, which played a pivotal role in the design and implementation of this study. Moving further, this chapter will outline the step-by-step procedure employed throughout the study. The research process, including data collection techniques, will be detailed, shedding light on the methods used to capture and analyze relevant data. By providing a comprehensive account of the chosen methodology, the participant sample, ethical considerations, and the research procedure, this chapter aims to establish a robust framework for the subsequent analysis and interpretation of findings. The meticulous attention to methodological rigor will contribute to the validity and reliability of the study's outcomes, advancing our understanding of HD and its multifaceted dimensions.

Rationale

In a recent investigation on the portrayal of HD in popular media, I identified a gap in literature regarding success stories of individuals with HD/HDCs (Quayat, 2021). To explore this further, I turned to the unfiltered world of online communities, particularly on *Facebook,* which serves as a common platform for individuals with shared interests. By searching for relevant keywords such as *hoarding, hoarding disorder,* and *decluttering*, I discovered several related groups. Within these groups, members shared before-and-after pictures of their homes, offered support and encouragement to each other, and discussed their experiences with therapy alternatives, such as online communities. This observation led me to formulate research questions of this study:

1) What is the nuance and flow of the online HD communities?

2)What are the key features of participation in online HD communities?

To address these questions, DE is an appropriate methodology as it allows for both observation and active participation in these communities, fostering relationships to gain a deeper understanding of this condition and challenging negative representations of HD. Moreover, DE aligns with my personal values as a researcher who embraces constructivism, socio-cultural theory, and interpretivism.

Sampling

The study employs purposeful, stratified sampling, as described by Creswell & Poth (2018). In qualitative research, this method involves selecting knowledgeable individuals from relevant subgroups related to the phenomenon of interest, allowing for meaningful comparisons. The authors highlight its usefulness in obtaining rich information with limited resources. Given the focus on understanding the experiences of specific online HD support groups, this sampling strategy is well-suited. Considering the several types of groups available, detailed descriptions and comparisons of the data will provide a comprehensive understanding of the topic.

To address the different cohorts of individuals affected by HD, as outlined in the literature review, this study focuses on four subgroups: individuals struggling with HD, family members of HD individuals, children of HD individuals, and a public group associated with HD. This selection aims to encompass the interpersonal contexts and age demographics relevant to HD. These subgroups have been observed across various online platforms, including the discussion boards from different websites and social media sites. The literature suggests different approaches to sample size, with some emphasizing the amount of data needed for insight and others recommending 8-30 participants for qualitative research (Creswell & Poth, 2018; Mertens, 2020). To manage the data effectively, ten threads of conversation or interactions have been randomly selected from each subgroup, resulting in a

total of 40 data sources. This approach provides sufficient data to capture the nuances of each

group and facilitate meaningful comparisons while attempting to stave off any potential

biases of the researcher (Mertens, 2020). In efforts to maintain current, and therefore assumed

most relevant data, posts which were older than one year of the date of collection were

excluded.

Ethical Considerations

   After successfully completing the *Tri-Council Policy Statement* (TCPS 2): *Ethical*

conduct for research involving humans tutorial (Government of Canada, 2018) (Appendix

A), approval from the Athabasca Research Ethics Board (REB) was obtained. As internet

research is an evolving field of research, it is imperative to consider the privacy and ethical

care of those involved in online studies. As illustrated below, this study only involves

accessing information from publicly accessible groups and, due to the observational nature of

the study, informed consent was not required.

   According to the TCPS 2 (2018) tutorial, REB approval can be granted if the data

used in the study is both publicly accessible and free from "reasonable expectations of

privacy" (Module 2: Defining Research). In the present investigation, the selected websites

and social media platforms are all openly accessible to the public, including the comments

that have been collected and analyzed. Kitchin (2007) notes that private and public spaces

should not only be categorized based on the accessibility of information based on the

presence of a steward, but also in regard to the intended audience and perceived privacy.

Moreno et al. (2008), point out that individuals who post groups are often under the

impression that others reading the posts are of similar community, which is supportive of

their worldviews. Elgesem (2002) highlights that in such cases, the information shared may

be more personal, as there is a perception of privacy. However, Esalella and Ardevol (2007)

argue that online users often formulate unrealistic expectations of privacy, therefore

questioning of the dichotomy of public and private spaces. The authors suggest that in seeking REB approval, researchers should consider aspects such as the degree of intimate information being shared, if users can restrict access to their personal information, and the accessibility of the space. In the case of many online forums and social media platforms, individual users have dominion over what they feel comfortable posting; both as profile/identifying information and their comments to discussions and can limit the amount of information shared with other users. Therefore, it could be argued that if a person does not wish to share information, either as a post or access to their personal profile, they have the means to ensure their privacy. Moreover, many public online groups encourage new users, with populations in the hundreds/thousands. Eysenbach and till (2001), suggest that such groups can be thought of more as public spaces, therefore garnering minimal perceived privacy expectations.

Another important consideration is the risk of harm to participants and the safeguarding of information (TCPS 2, 2018). Kitchin (2007) notes that with non-intrusive online research, in which the researcher is a passive observer, as is the case in my research, harm is minimal and therefore would not cause any damage to participants. Moreover, in this study, all usernames and identifying information have been omitted, all comments have been paraphrased. As a result, participants' privacy has been protected and therefore, informed consent was not required (TCPS 2, 2018). Furthermore, participants' data has been stored in password-protected, encrypted, files on a private computer. The computer used is safely always stored and password-protected. All participants' data has been kept anonymous, with no personal identifiers when disseminated and only the researcher and supervisors will have access to identifiable data. There are no known conflicts of interest.

Data Analysis

In this project, thematic analysis (TA) was employed for data analysis. Braun & Clarke (2006) have noted that TA proves to be a useful tool in quantitative research, as it is applicable across a range of epistemological and theoretical approaches. They mention that it is compatible with the constructionist paradigm, as it embraces multiple perspectives and realities to richly describe phenomena (p.79). Furthermore, they point out that using TA involves searching and analyzing across (multiple) data sets to find repeated patterns of meaning (p.91). For this study, TA has also been deemed appropriate as it permits a flexible approach and a code-development system that is relevant and useful for inexperienced researchers, such as me, to extract meaning and nuance from the information gathered (Kriukow, 2020).

The process of conducting thematic analysis (TA) in this study aligns with the steps proposed by Braun and Clarke (2006). To initiate the analysis, data will be collected from various sources. Subsequently, the data will be read multiple times while generating initial notes. As per the authors' guidance, this iterative process aids in the identification of primary codes from the data sets. Codes are then collated into themes based on the emergence of patterns in the coded data. The analysis and refinement of the themes occurs throughout the study, varying based on the content of the data sets. Each theme is assigned a unique name and definition to aide in the in management and analysis of the data sets. Furthermore, the themes are reviewed for consistency and/or discrepancy across the data. To maintain alignment with the theoretical framework, I will then position the data within one (or more, when applicable) of the quadrants as represented earlier in Figure 1. This approach enables the incorporation of interplay among varying worldviews into the analysis of the data sets. Finally, the results will be presented in such a manner as to answer the research questions.

Quality

Gibbs (2012) identifies four key features for establishing quality in qualitative studies: reliability, validity, generalizability, and credibility, which I will elaborate on.

One limitation of this study is its sole reliance on a single researcher, which may raise concerns about the study's reliability (Mertens, 2020). However, to address this issue, a comprehensive research log will be maintained (Appendix B), documenting the methods and procedures employed during the coding process. This practice enhances the reliability, as another person could replicate the same procedures. Moreover, the utilization of a theoretical framework contributes to the study's reliability, as the initial categorization is based on the previously mentioned quadrants. Consequently, the initial understanding, classification, and subsequent data analysis are situated within a conceptual framework that can be replicated. Furthermore, the presence of only one researcher results in high interrater reliability, as there is no potential for miscoding caused by multiple researchers (Mertens, 2020). Additionally, concerns about subject reliability and subject bias are minimal, as the data collected remains fixed and does not necessitate interactions with the researcher (Gibbs, 2012).

Gibbs (2012) defines internal validity as the extent to which a study's research questions are adequately addressed. Given the diversity of data, along with the inclusion of multiple realities from individuals within the subgroups, there is a high likelihood that the research questions will be sufficiently answered. Furthermore, as the author points out, the fact that the study captures a snapshot of posts within the groups without any direct interaction with the researcher helps avoid potential threats to validity, such as client-history and undue influence of participants.

According to the author, generalizability pertains to the degree to which the findings of a study can be applied to other populations. Since the targeted subgroups exhibit variability and relevance to the research question, the results may be applicable to other

similar groups. Additionally, the author mentions that using different online modes of communication to gather data can help mitigate potential setting issues. However, it is essential to note that in qualitative research situated within the constructivist paradigm, as emphasized by Creswell & Poth (2018), Gibbs (2012), and Mertens (2020), the primary focus is on capturing rich descriptions of experiences rather than seeking generalizability. Purposive sampling and the comprehensive description of participants' experiences contribute to the study's dependability, which will be further ensured through regular reviews and debriefing of the data with the researcher's supervisors.

Lastly, credibility encompasses the level of detail provided within a study to demonstrate its processes and procedures (Gibbs, 2012). To enhance confirmability in qualitative research, Darawsheh (2014) recommends the utilization of reflexive journaling. In accordance with this suggestion, a journal will be maintained, documenting rationales for decisions, procedures employed, as well as any biases and assumptions made throughout the project. Additionally, the use of bracketing, as proposed by Darawsheh (p. 565), will aid in distinguishing assumptions and biases from other procedures.

Challenges of the Study

As ethnographic research has not been conducted in HD groups, a few challenges accompany this research project.

Firstly, due to the uniquity of this study, within this specific area of interest, there are limited resources available to serve as guides. Though other DE studies in differing fields/focuses were used as rough estimates, there is a degree of uncertainty that accompanies this endeavour. Though the reflexive journal does afford the opportunity to highlight and explore any issues that may arise, being a novice researcher adds to this dimension of challenge. Thankfully, leaning into my colleagues and supervisors for support and guidance is a welcomed support and solution to this challenge.

Secondly, balancing the data size may prove difficult. On the one hand, I want to explore as much data as possible in efforts to provide the richest description of the participants' experiences; thus, creating a robust data set (Mertens, 2020). However, I realize that by analysing the initial posts of participants, the discussion threads that accompany them and any relevant artifacts (i.e., emojis/pictures etc.), the amount of information quickly becomes overwhelming. Moreover, I feel it prudent to maintain equal distribution of the sampling to afford equal representation of the diverse groups' themes. However, this is a challenge as some groups were more represented than others. This will be a consideration when determining the sample size and number of posts represented, as is ensuring a data sample size that will be manageable for a novice researcher (Kriukow, 2020).

Significance of the Study

Ensuring counsellors can provide culturally competent support to individuals grappling with HD is of utmost importance. However, our current comprehension of the condition, along with available treatment modalities, remains limited without gaining insight from an insider's perspective. Regrettably, the literature lacks ethnographic and culturally informed approaches to studying HD. Many international studies tend to generalize western-based perceptions of symptoms and treatment interventions. This study aims to shed light on the rhetoric surrounding HD, extending beyond traditional therapeutic settings. The findings will unveil the factors influencing individuals' success, the challenges they encounter, and the support they receive from others. The knowledge acquired from this study can serve as a foundation for comprehending HD in a more person-centered and ecology-focused manner.

Furthermore, this study sets the groundwork for future research involving individuals from different contexts, in online groups functioning in various languages. By endorsing alternative approaches to grasp mental health concerns and letting go of the conventional hierarchical research approach, we can allow the experiences of the true experts—the

individuals—to lead the community toward a more profound understanding and alliance. The data collected and analyzed, as outlined in the following chapter, will highlight the ways in which the preceding goals have been met.

Chapter 5: Results

This section presents the culmination of a comprehensive investigation, firmly grounded in the realm of digital ethnography, aimed at gaining an insider's understanding of Hoarding Disorder (HD). The study thoughtfully examines the phenomenon from four distinct participant groups: individuals grappling with HD, the resilient children of individuals affected by HD, the empathetic friends and family members supporting their loved ones, and the broader perspective of the public. To assemble a rich tapestry of insights, ten online posts, the associated comments, and artefacts, were randomly selected and meticulously collected from the online, public forums. These forums serve as a fertile source for gathering authentic narratives and experiences, reflecting the genuine challenges and triumphs encountered by those connected to HD. The data was subjected to rigorous cataloging and systematic thematic analysis, allowing for the identification of recurring patterns, underlying emotions, and the unique lived experiences of each participant group (Kriukow, 2020). To enhance the interpretive framework, I will contextualize the gathered data within the integral lens of Ken Wilber's AQALs model (1995), providing a holistic understanding of the phenomenon. By considering the internal and external experiences of the individuals, the collective elements within the groups, and the surrounding cultural aspects, the interconnectedness of various facets that underpin HD will be elucidated. This section unfolds by presenting the profound insights gleaned from each participant group. These insights will then be compared across the groups, in efforts to highlight and contrast similarities and differences, which may offer a deeper comprehension of the intricacies surrounding HD.

Individuals with Hoarding Disorder

This group comprises individuals who self-identify as struggling with HD, though it is not known if they received a formal diagnosis. This public group recognizes the sensitive and

embarrassing nature of HD. With an acute appreciation for the lack of safe spaces available

for affected individuals to gather, the group fosters an honest and judgement-free

environment. The members are encouraged to openly share their struggles, successes, and

setbacks in this haven, thus finding solace and validation. Group members can initiate a

conversation and are able to include varying artefacts. In turn, group members can respond

with their own comments/reactions and other artefacts. One feature of this group is the

upwards and downwards voting, which represents dis/approval for the content. Like a rating

scale, the more up/down-wards votes a post and/or response receives, the more/less visible

the content becomes within the group. The thematic analysis of the content revealed thirteen

emerging themes, which were placed in one of the four AQALs quadrants: (a) *I*, (b), *It,* (c)

We, and (d) *It*; representing the inner thoughts/feelings of an individual, a person's behaviour,

the common experiences and values within a cohort of people, and the systemic factors

around them, respectively (Wilber, 1995). The results are shown in Table 1 (see Appendix C

for thematic codes and AQALs classification).

Within the *I* quadrant, six themes were found: (a) *obstacles for making progress*, (b)

negative personal emotions, (c), *positive personal emotions,* (d) *past issues/history of HD*,

(e), *self-talk* and, (f), *negative comments/interactions/feedback*. These themes illustrate: (a)

trauma, emotional attachment to items and struggles with motivation, (b) the difficult feelings

such as overwhelm, discomfort, self-hatred, and blame, (c) feelings of relief from

successfully clearing items, (d) longitudinal experiences with HD, (e) the inner dialogue used

to improve habits and, (f) disagreement of opinions with other members. The *It* quadrant

contained five themes: (g) *suggestions/recommendations and advice,* (h), *negative*

behavioural issues from HD, (i), *positive personal behaviours,* (j) *how I started making*

progress/what I do, and (k) *description of hoarded items*. These themes touched on: (g)

practical ways to improve and manage personal healing, items, and daily routines, (h) the

tendency to refill cleared spaces, and relationship struggles, (j) descriptions of the steps and/or strategies that may facilitate positive change and, (k) the items they preferred to keep and/or had struggles parting with. The *We* quadrant held two themes: (l) *positive comments/interactions/feedback* and (m) *shared experiences/seeking connection.* These themes captured: (l) support, encouragement and appreciation for one another and their successes, and (m) group members asking for clarification and advice. There were no themes which fell into the *We* quadrant.

The emergent themes demonstrate that group members place a high discussion priority on finding ways of self-soothing, managing their items and finding useful alternative ways of achieving progress. The least amount of commentary was devoted to the actual items being hoarded. This shows that the items themselves are not the focal point of the group but rather the ways in which to manage the items and the person struggling with HD. This is contrary to the *DSM-5* classification, which demonstrates that people with HD show low-insight to their issues (American Psychiatric Association, 2013) as the group members were able to openly discuss their struggles and were actively seeking improvement. However, as congruent with the *DSM-5*, the themes show emotional distress and overall difficulty with respect to accumulating and discarding items, along with HD spanning various age demographics in a person's lifetime (p.251-253). As first-hand accounts are not found in the current literature, new insights with respect to the self-talk strategies, general emotional support and encouragement within the group, have surfaced.

Table **1**

Individuals with Hoarding Disorder: Thematic Analysis and AQALs Grouping

Theme and Ranking of Frequency	Sub-Themes	Supporting Paraphrased Quotes	AQAL Quadrant
2. Obstacles for making progress	1. Trauma 2. Emotional attachment to items 3. Starting/finishing is the hardest	"I get stuck on trauma, and it becomes all I ever think about" participant 9 I get stuck when start going through things and all the memories come back." Participant 19 "I'm always the same – I can't get started" participant 13	I
3. Negative personal emotions	1. Negative emotions 2. I'm overwhelmed 3. Emotional distress from cleaned area	"Every day is hard, and I can't see it getting better" participant 3 "It's everywhere I look, and I can't escape it – it's just overwhelming" participant 21	I
5. Positive personal emotions	1. I am glad it has gone 2. I prefer relationships to things 3. I love cleared spaces	". . . but once it's gone, I never want it back" participant 8 "If I had to pick, I'd choose things" Participant 13 "I'll never go back – my cleared space is amazing" participant 23	I
8. Past issues/history of HD	1. Childhood issues related to hoarding 2. In the past, I preferred things to relationships 3. Hoarding issues since childhood	". . . it goes back a long time – as long as I can remember – it started when I was young" Participant 3 "I used to prefer my stuff to spending time with people" Participant 8	I
10. Self-talk	1. Self-talk about keeping items 2. What do I really need? 3. Self-Talk Used to Stay on Track	"It's just 10 more minutes and then you can rest" Participant 11 "Try asking if this is something that you can use every day, not some day" Participant 17	I
11. Negative comments/interactions/feedback	1. This is not useful 2. Why this would not work for me 3. Negative comment removed by moderator	"As a hoarder, I don't think this could really work" Participant 29 "This would never work for me" Participant 5 "Your comment has been deleted as it violates the rules of the group" Participant I	I

1.Suggestions/recommendations and advice	1. Suggestions for self-healing to deal with hoards 2. Suggestion to help with keepsakes 3. Recommendations for seeking help	"Take a breather and get your emotions in check – journalling can be a game-changer" participant 5 "Try getting to know why you're holding on to your things. If it's not something you love, you can leave it" participant 23 "Maybe think of online counselling – you can talk to people all over the country" participant 17	It
4. Negative behavioural issues from HD	1. I struggle to clear 2. The house is different after its cleared (sound/feel) 3. I'm not used to the cleared space	"I want to, I do but I just can't get rid of it -it just moves from one place to the other" Participant 22 "I get this eerie feeling when I do clear a space – like now it's empty" participant 4 "It takes me a long time just to feel comfortable in my own space. It doesn't feel right" Participant 6	It
7. Positive personal behaviours	1. I'm cleaning everyday 2. Noticeable progress made 3. I've finally started to clear	"I've got a schedule now and I'm doing a bit each day" Participant 11 "It's not what I had planned to get done but at least I got this far!" Participant 5 "I spent a lot of time thinking but today I started!" Participant 10	It
12. How I started making progress/what I do	1. Good relationships help my hoarding 2. I try to buy helpful things (i.e., storage/cleaning) 3. Coping mechanisms	"The best therapy and way to change is through your friends" Participant 24 "Now, I spend my money on organizing things like boxes – useful things" Participant 7 "You have to find what works for you so that you can get through it" Participant 14	It
13. Description of hoarded items	1. Description of Items Left to Clear 2. I hoard clothes 3. I hoard paper	"It's a lot of old documents – taxes and stuff- you never know when you need it" Participant 23 "Mine is mostly clothes – too many clothes" Participant 20 "I'm stuck on paper – all kinds, it doesn't matter" Participant 17	It
6. Positive comments/interactions/feedback	1. Supportive comment 2. Thank you 3. Praise for personal progress	"You've got this!" Participant 24 "I don't know where I'd be without this group" Participant 2 "You're doing so well, and every day is just a little bit more than yesterday" Participant 5	We
9. Shared experiences /seeking connection	1. Asking for clarification 2. Clarifying comment 3. Does anyone else have this issue?	"Did I get that right?" Participant 3 "It's more like this..." Participant 20 "Please tell me I'm not alone in this" Participant 18	We

The analyzed artefacts included emoticons, pictures, links to external resources, and up/down votes (see Appendix C for the full artefacts analysis). The three most frequently occurring artefacts, as illustrated in Table 2, are: (a) *links to external resources,* (b) *crying face* and, (c) *smiling face*. These were placed in the *It*, *I*, *I* quadrants as they pertained to the actions/behaviors and inner thoughts of the participants, respectively. Interestingly, none of the posts received a downwards vote however, upvotes were found across all quadrants, ranked as: (a) 455/*It* quadrant, (b) 235/*I* quadrant, (c) 100/*I* quadrant and (d) 0/ *Its.* This demonstrates that the group prioritized finding supportive strategies, communicating their emotions, and providing positive support to one another.

Table **2**

Individuals with Hoarding Disorder: Artefacts Frequency and AQALs Distribution

Artefact Name	Artefact Image	Frequency	AQAL Quadrant
Link		6	It
Crying		4	I
Smile		4	I
Upvote		235 455 100 0	I It We Its
Downvote		0	0

To capture the data holistically, Figure 2 represents the data sets (*Note:* One upvote arrow represents ten upvotes). As the data set shows, the inner thoughts and ways to change within the *I* and *It* quadrants are most prevalent. The sense of community is present, whilst the contextual factors do not appear as robust in visibility as the others.

Figure **2**

Individuals with Hoarding Disorder: Thematic Analysis, Artefacts and AQALs Quadrant Results

Children of Individuals with Hoarding Disorder

This group consists of individuals who claim to have (a) parent(s), who struggled with HD, though it is uncertain if a formal diagnosis of HD had been received. This public group acknowledge the unique challenges growing up and living with HD parents in both child and adult hood. Though members are free to reply to posts made by the owner of the group, a member cannot create an original post. Despite this aspect of initiating dialogue, members were encouraged to openly share their experiences and responses, along with including varying artefacts. As stated before, ten posts were randomly selected, with their responses thematically coded and placed within an AQALs quadrant. A total of ten themes emerged, as outlined in Table 3 (see Appendix E for thematic codes and AQALs classification.

The *I* quadrant held two themes: (a) *negative emotions* and (b) *self-talk.* These themes capture: (a) the emotional struggles encountered by the participants and, (b) the inner messages the participants used to help support themselves. The *It* quadrant held three themes: (a) *negative outcomes/behaviors from HD experience,* (b) *comorbid condition*s and, (c) *positive behaviours.* These themes highlight: (a) the adverse impact of living within an HD home, (b) addition conditions compounding the HD behaviours and, (c) the ways members were actively improving their lives. The *We* quadrant revealed three themes revealed: (a) positive *comments/interactions/feedback*, (b) *seeking connection* and, (c) *recommendations and advice*. These themes illustrate: (a) friendly and supportive group interactions, (b) positive inter-member connections and, (c) the use resources and strategies members could use to make positive progress. The *Its* quadrant held two themes: (a) *criticisms of HD* and, (b) *descriptive HD.* These themes concerned: (a) shortcomings of the current model of understanding HD and, (b) the diagnostic features and criteria of HD. This data demonstrates the group's prioritization of sharing their unique experiences and supporting each other as they discussed the ways they had been, and still are, affected by their parents' struggles. Though the data is like the current literature in that there is a tone of frustration towards the person with HD by their family members (Bratiotis & Woody, 2020; Gargiulo et al., 2017; Tolin et al., 2008), this group prioritizes their struggles over their parents'. This is contrary to Tolin's et al.'s (2008) research, which indicates family members feeling compelled to support their family members despite the negative living arrangements. As the current literature is lacking on first-hand accounts of children of people with HD, this data set provides a unique perspective of consideration.

Table **3**

Children of Individuals with Hoarding Disorder: Thematic Analysis and AQALs Grouping

Theme and Ranking of Frequency	Sub-Themes	Supporting Paraphrased Quotes	AQAL Quadrant
6. Negative emotions	1. Highly negative language associated with children of hoarders' experience (i.e., abusive/imprisoned/held hostage) 2. Admin intervention to repair interaction 3. Trigger inducing	"Childrens needs are not met as they are imprisoned and neglected by their parents" Participant 5 "We are here to support you, there's no need to attack each other" Participant I "There should be a warning on this – total trigger!" Participant 24	I
7. Self-talk	1. Positive affirmations towards personal improvement (i.e., you can break the cycle) 2. Don't judge/don't judge me	"Just stay focused – you totally can get there!" Participant 6 "I would never judge someone for what I don't know about them, and I expect the same" Participant 28	I
2. Negative outcomes/behaviours from HD experience	1. Negative effects of parents' behaviour 1. Description of negative behaviours/relationships 3. Co/dependency	"Just being normal was never a thing – doing normal things just couldn't happen" Participant 22 "She'd just ignore me – I'd disappear into the pile" Participant 12 "I started realizing I was one of her things – and we needed each other" Participant 7	It
3. Comorbid conditions	1. Hoarding disorder and narcissistic personality disorder 2. Comorbid conditions associated with HD	"Understanding how these two conditions go hand in hand allow us to name the reasons why our needs have not been met" Participant I "There are many other things that go with HD" Participant 9	It
9. Positive behaviours	1. Positive attempts to deal with children of hoarders' experiences 2. Descriptions of healthy relationships 3. Healing/the healing process	"I decided to get my own therapist and work on my own issues" Participant 31 "You know you have good people in your life when they don't act like they own you" Participant 43 "It is something you have to work on for years" Participant 37	It
1. Positive Comments/interactions/feedback	1. Shared experience 2. Agree 3. Supportive comments	"That's exactly like it was for me" Participant 3 "Totally agree -same!" Participant 9 "You did what you could – we all did" Participant I	We
4. Seeking connection	1. Disagree/disagreement with previous post/comment 2. Clarification of post/comment content 3. Where do we go from here?	"I don't think so – it wasn't like that for me" Participant 3 "I'm not sure this is what you mean but for me..." Participant 4 "I know all of these things, but what's next?"	We

10. Recommendations/advice	1. Links to resources 2. Suggestions for help/resources	"Finding help that focuses on you is the most important thing – don't get the same therapist" Participant 31	We
5. Criticism of HD	1. Critic of understanding of hoarding disorder and/or comorbid conditions 2. Critic of media portrayals of hoarding disorder 3. Call for more research	"I definitely think we need a better understanding" Participant 19 "The media makes it look way different than it really is" Participant 26 "More research is needed – there's a lot missing from what we currently know" Participant 10	Its
8. Descriptive HD	1. Clinical terminology (i.e., anxiety, OCD, NPD etc.) 2. Hoarding disorder behaviours 3. Classification of Hoarding Disorder (i.e., reference to DSM-V or other Classifications)	"HD is no longer part of OCD" Participant I "People with HD have it both ways – it's coming in and going out that's the problem" Participant 27 "The DSM-5 now views HD as its own disorder" Participant I	Its

The numerous artefacts, consisting of emoticons, GIFs, links to resources and pictures, were collected (see Appendix F for artefacts analysis). The top three artefacts have been represented in Table 4.

The most common artefacts were: (a) *like,* (b) hug and (c) *love* emoticons. These represent: (a) a member's support of a post, (b) a member providing emotional support and, (c) a member's deep resonance with a post. There was a total of 134 *likes*, which were distributed within the AQALs quadrants as: (a) 9/*I*, (b) 13/*It*, (c) 59/*We* and (d) 53/*Its*. 50 *hugs* were distributed as: (a) 29/*We,* (b) 17/*Its*, (c) 2/*I* and, (d) 2/*It*. The *love* emoticon had a distribution of: (a) 68*/We,* (b) 40*/It,* (c) 19/*Its* and, (d) 3*/I*.

Consistently, the most emoticons were placed in the We quadrant and the fewest in the I, supporting the group's affinity for personal connection and understanding, within a judgement-free setting. Moreover, the top three artefacts are all positively supportive, which is also congruent with the tone and characterization of the group and its members.

Table **4**

Children of Individuals with Hoarding Disorder: Artefacts Frequency and AQALs

Distribution

Artefact Name	Artefact Image	Frequency	AQALs Quadrant
Like		134	9I 13It 59 We 53 Its
Hug		50	2 I 2 It 29 We 17 Its
Love		130	3 I 40 It 68 We 19 Its

The combination of the data sets has been illustrated by Figures 2. (*Note:* Due to the high volume of artefact, quadrants *We* and *Its* are represented in multiple figures).

Figure **3**

Children of Individuals with Hoarding Disorder: Thematic Analysis, Artefacts and AQALs Quadrant Results

Friends and Family Members of Individuals with Hoarding Disorder

The individuals in this group were self-proclaimed friends and/or family members of individuals struggling with HD. As before, it is not known whether the family members had a *DSM-5*-based diagnosis of HD. This public group allows for members to begin their own conversations, as well as being able to interact/respond to other posts. Artefacts were also used to enhance their interactions, including emoticons and links to external resources. As before, ten randomly selected posts were collected, thematically analyzed, and distributed within the AQALs quadrants; as illustrated in Table 5 (see Appendix G for thematic codes and AQALs categorization).

The *I* quadrant revealed three themes: (a) *negative emotions*, (b) *self-talk* and (c) *past issues/history around HD.* These themes address the: (a) members' feelings of inadequacy in providing support, (b) members' personal thoughts and (c) evolution of their HD experiences. There were also three themes in the *It* quadrant: (a) *recommendations and advice*, (b) *negative behaviours* and (c) positive behaviours. These themes captured the: (a) participants asking for help, (b) behaviours their loved ones struggled with and, (c) the helpful strategies to instigate change. Four themes surfaced in the *We* quadrant: (a) *shared experiences and seeking connection*, (b) *what is needed*, (c) *technical problems* and (d) *negative feedback/comments*. These themes spoke to the: (a) participant' support and understanding, (b) participants' best course of personal action, (c) software issues preventing connection and, (d) participants' negative commentary. In the *Its* quadrant, three themes were found: (a) *obstacles and complications*, (b) *explanation of HD's struggles* and (c) *description of behaviour*. These themes describe: (a) the issues surrounding their loved-one's progress, (b) perspective and rationalization surrounding HD tendencies and (c) discussions of loved-one's behaviours.

This data demonstrates the group's main interest is in finding practical ways of assisting and supporting their loved ones struggles with HD. As with the first group, the main point of discussion was sharing resources so that individuals could customize their approach to the items and their feelings. The second main theme, which highlights feelings of frustration within the situation, echoes the current literature surrounding this cohort. (Tolin et al., 2008; Wilbram et. al., 2008).

Table **5**

Friends and Family Members: Thematic Analysis and AQALs Grouping

Theme and Ranking of Frequency	Sub-Themes	Supporting Paraphrased Quotes	AQAL Quadrant
2. Negative Emotions	1. Feeling confused/unsure what to do 2. Feeling overwhelmed	"I have no idea how to help" Participant 11 "It's so overwhelming" Participant 9	I
8. Self-talk	1. Want to help but can't 2. Would this really be helpful? 3. Description of 'what I wish it would be like"	"I'm pretty powerless" Participant 1 "You could go in there but what if it makes it all worse? Participant 25 "I have these dreams of everything going back to normal" Participant 2	I
12. Past issues/history around HD	1. Childhood instances affecting hoarding	"It wasn't easy growing up, I'm pretty sure that's where it started" Participant 5	I
1. Recommendations/advice	1. Link to Resources 2. Asking for advice 3. Recommendations on how to approach cleaning a hoard	"Any advice welcome" Participant 1 "I need some tips on how to clean up without getting them upset" Participant 23	It
5. Negative Behaviours	1. Family relationships are suffering due to family member's hoarding 2. Concerns about health 3.Consequences of current situation (i.e., infestation or sickness)	"We don't connect the way we used to" Participant 19 "I'm worried about his cough -it's definitely getting worse" Participant 16 "I thought I saw a rat the last time I was over" Participant 16	It
6. Positive behaviours	1. Action plan mentioned 2. Setting boundaries 3. Hoarder's perspective – how I am learning to understand and cope	"We've started setting small goals everyday" Participant 33 "I try to understand but there are times I have to walk away" Participant 29 "It helps me to understand what he's going through more" Participant 14	It
3. Shared experiences /seeking connection	1. Shared experience 2. Supportive comment 3. Comment shows sensitivity	"I do exactly the same thing" Participant 13 "You're trying really hard – they're lucky to have you" Participant 3 "It's okay to feel that way – it's normal" Participant 7	We
11. What is needed?	1. Hoarders need support and presence 2. Hoarders need love	"The most helpful thing is just having someone there – you don't have to help" Participant 25 "I've found that just letting them know I love them is all that works" Participant 7	We

12. Technical Problem	1. Administration or technical problem	"I can't seem to post this" Participant 6	We
13. Negative feedback/comment	1. Insensitive response	"Sounds a bit crazy to me" Participant 20	We
4. Obstacles/complications	1. Comorbid health/mental health conditions mentioned 2. Trauma mentioned 3.COVID complicating relationships with hoarders	"If you look around, you'll see that so many things can impact the condition" Participant 25 "Trauma is one of the worst even though they don't really talk about it enough" Participant 24 "Since lockdown, it's been even harder to get him out" Participant 18	Its
7. Explanation of HD's struggles	1. Family member doesn't recognize their problem 2. Explanations of family members' hoarding behaviour 3.Family member can't care for themselves	"They don't really understand what I mean when I tell them the house is messy" Participant 8 "I know she's been through a lot – things definitely got worse after it happened" Participant 30 "It's getting worse because they're just too old" Participant 18	Its
9. Description of behaviour	1. Description of family members' behaviour 2. Family members' house isn't safe	"They stay around watching TV all day – just in that chair" Participant 18 "I'd like to get them out of there – it's falling apart!" Participant 29	Its

The three most frequently occurring artefacts, represented in Table 6 (see Appendix H for full artefacts analysis), are: (a) *links to additional resources/websites*, (b) *happy face holding a flower* and, (c) *smiley face.* These were distributed amongst the AQALs quadrants as: (a) 10/ *It,* (b) *1/It* and *1/We* and, (c) *1/I* and *1/It.*

These artefacts are consistent with the themes and the quadrants mentioned earlier, as they reflect positive, supportive connection and the desire for change. Interestingly, the *Its* quadrant did not receive any artefacts in the threads, which may represent the low prioritization of societal/contextual and/or systemic factors.

Table **6**

Friends and Family Members: Artefacts Frequency and AQALs Distribution

Artefact Name	Artefact Image	Frequency	AQAL Quadrant
Link to resource	Direct link to site or other resource	10 (Note: this was never used by the participants)	It
Happy face with flower		2	It We
Smiley Face		2	I It

To further enhance the visual representation of the three data sets, Figure 4 encapsulate the 4 AQALs quadrants (Wilber, 1995), as well as the subthemes and artefacts within them.

Figure **4**

Friends and Family Members: Thematic Analysis, Artefacts and AQALs Quadrant Results

The General Public

This group consists of individuals who are interested in the media's portrayal of HD, specifically with respect to the television shows. It is uncertain how many, and to what capacity, any of the participants have a relationship to HD beyond that of being viewers of the shows. Within this forum, members are not able to generate their own posts, but can react/comment to the show that can be viewed. Participants share their thoughts and ideas about the shows, as well as can respond and react to other comments. Artefacts were also used within this group, which were emoticons. A key feature of this group was the option to dis/like a post/comment, which could influence the visibility of a post and/or the participant. The thematic analysis of the ten posts, and their respective comments, are illustrated below in Table 7. Nine themes surfaced from the analysis (see Appendix I for thematic codes).

Quadrant *I* was characterized by three themes: (a) *negative view/opinion/comment*, (b) *positive view/opinion/comment* and (c) *personal desire to change.* These themes captured the participants': (a) negative reactions to the program, (c) positive reactions to the program and (c) reasons for wanting to change. Three themes were also found in the *It* quadrant: (a) *descriptive/symptomology*, (b) *shows are helpful/educational* and, (c) *how to address hoarding*. These themes touched on: (a) the behaviours often associated with the diagnostic criteria of HD, (b) the supportive ways participants could gain from the shows and (c) strategies and methods of managing and coping with hoarding tendencies. The *We* quadrant held two themes: (a) *trying to understand and connect* and (b) *personal connection to hoarding.* These themes illustrate: (a) participants' efforts to find mutual understanding and (b) the ways participants were personally involved in HD, such as through a family member.

This data set shows that the main focal point of this group was to discuss the individuals in the show, who struggle with HD, with an undergirding, negative tone. This is congruent with a preliminary thematic analysis I conducted in 2022 which investigated the

media's portrayal of the condition and the public's perception of it. Moreover, the literature demonstrates that stigma towards individuals with HD is prevalent, as othering and distain causes a problematic distance between those with and without HD (Bates et al., 2020; Corrigan & Watson, 2002; Lepsetler, 2011; Strong, 2000). However, the data demonstrates that there was also a prevalence for participants to connect with each other, empathize with the individuals portrayed on the show and consider contextual factors at play. These are more contrary to the literature.

Table **7**

The General Public: Thematic Analysis and AQALs Grouping

Theme and Ranking of Frequency	Sub-Themes	Supporting Paraphrased Quotes	AQAL Quadrant
1. Negative view/opinion/comment	1. Negative judgement about the hoarder 2. Pity for people in the show 3. Negative language used	"What a wicked woman for putting her family through that" Participant 4 "I feel sorry for these people" Participant 7 "They're disgusting" Participant 12	I
2. Positive view/opinion/comment	1. Agree 2. Supportive comment 3. Supportive comment for hoarder	"Definitely – read my mind!" Participant 5 "They seem like nice enough people – at least they're trying" Participant 11 "At least she's getting help" Participant 9	I
9. Personal Desire to Change	1. I like getting rid of my extra stuff 2. I need to get organized 3. Wanting to clear my house to make it easier on others in the future	"I love clearing out my space- I do it at least once a year" Participant 33 "Watching this show makes me realize how badly I need to get organized!" Participant 44 "I need to clean – I don't want to be a burden to my family" Participant 42	I
5. Descriptive/Symptomology	1. Comment views hoarding as an illness 2. Description of hoarding behaviours 3. Description of hoard	"This is a sickness, it's not a choice" Participant 19 "It's making piles on top of piles, and you have no idea what's there" Participant 16 "I keep mostly clothes and newspapers – I don't know why!" Participant 22	It
7. Shows are helpful/educational	1. Watching shows helps my hoarding	"I watch these shows when I'm cleaning!" Participant 19 "This show teaches people about what it's like" Participant 39 "Lots of people can learn from these programs" Participant 38	It
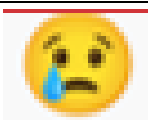
	2. This show can help people with hoarding 3. This show can educate people about hoarding		
8. How to address Hoarding	1. Self-talk associated with progress 2. Advice about what the hoarder in the show should do 3. Keep useful things	"I just tell myself to take it one step at a time" Participant 25 "These people should get a marriage counsellor! Participant 47 "Just toss the stuff you aren't using – it's the things you need that you need to keep!" Participant 49	It
3. Trying to Understand/connect	1. General opinion2. Empathizing about show content (i.e., people's actions/thoughts/feelings) 3. Empathizing about hoarding behaviour	"It must be hard being there, I can imagine it being tough" Participant 13 "Those poor people! Her son was such a sweetheart" Participant 17 "Nobody wants to live that way -it can't be a choice. I'm sure they're suffering" participant 19	We
4. Personal Connection to Hoarding	1. Shared experience 2. Commenter is a family member of a hoarder 3. Commentor mentions their progress	"I used to keep everything until I saw these shows and thought I needed to change" Participant 16 "My mum's a hoarder and this is exactly what she was like" Participant 11 "I've had to make changes, but I've gotten organized!" Participant 25	We
6. Contextual factors	1. Comment mentions negative media portrayals on the show (American portrayals) 2. Everyone in this situation has a responsibility not only the hoarder 3. Concerns for safety	"These shows are not very good at showing what it's really like" Participant 35 "That's not fair – everyone has some role" Participant 32 "I don't know why they're cleaning that place up – it looks like it's going to fall over" Participant 36	Its

Though Appendix J highlights the full artefacts analysis, the three most common artefacts, as shown in Table 8, are: (a) *heavily crying face,* (b) *smiley and hug face* and (c) *red heart* and *crying face* (equal prevalence). Their distribution amongst the AQALs quadrants is: (a) 16/*We*, (b) one/*I* and, (c) *seven/We* and *two/I*, respectively. Zero dislikes found within this data set, however there were 27,934 likes. These were distributed: a) *19,230 / We*, (b) *8,144 /I*, (c) *405/ Its* and, (d) 155/*It*. These artefacts are not congruent with the prevalence of themes of the analysis, empathic depictions, rather than negative ones, are more common within this aspect of the data set.

Table **8**

The General Public: Artefacts Frequency and AQALs Distribution

Artefact Name	Artefact Image	Frequency	AQAL Quadrants
Heavily crying face		16	We
Smiley & Hug face		11	10 we 1 I
Red heart		9	7 We 2 I
Crying face		9	7 We 2 I
Like		27,934	19,230 We 8,144 I 405 Its 155 It

The culmination of all data sets is represented in Figure 6. (*Note*: The golden *thumbs up*, represents 1,000 Likes in the Figures below, while. the transparent *thumbs up* represents 25 likes. This representation has been made for space -saving purposes).

Figure 5

The General Public: Thematic Analysis, Artefacts and AQALs Quadrant Results

Similarities Across the Data

The theme of shared experience emerged prominently within the analyzed narratives across the four distinct participant groups. Throughout the online communities studied, there was a prevailing desire among participants to establish connections with one another and to share their personal stories. This common thread was characterized by an underlying yearning to be acknowledged and comprehended, alongside the aspiration that the act of sharing their experiences might offer valuable insights to fellow members. This resonates with the psychological concept that the sharing of personal narratives can foster a sense of belonging and empathy among individuals facing similar challenges (Wilber, 1995). The recurring motif of seeking visibility, understanding, and mutual support within these digital spaces underscores the significance of communal storytelling in fostering emotional bonds and enhancing coping mechanisms within the context of HD. This theme may partially explain why CBT may be failing individuals with HD (Chou et al., 2020; Tolin, 2011). As Samoilov et al. (2000) point out: "the long-term effectiveness of CBT may be enhanced by going beyond symptoms at the cognitive level (i.e., intellectual meanings) and expanding therapeutic focus to the underlying, implicit emotional meaning" (p.373). In other words, if preliminary, therapeutic (CBT) sessions are aimed at thoughts and behaviours, the element of emotional recognition and understanding, as demonstrated by the groups, may be missed and therefore account for the high dropout rates in treatment (Chou et al., 2020; Tolin, 2011). Moreover, if therapists are struggling to understand their clients' situations, frustrations and dissonance may occur, which can rupture the therapeutic alliance and deter clients from seeking treatment (Holden, et al., 2019; Tolin et al., 2012). However, the theme matches with the very nature of these groups, as members attempt to find refuge and understanding among the safety of its community.

A second compelling theme that emerged across all participant groups was the phenomenon of self-talk, representing the internal dialogues, mantras, and narratives individuals employ to regulate their thoughts and behaviors. This theme held significance due to its ubiquity among the diverse groups, despite variations in the content and nature of inner monologues within each subgroup. This finding is in harmony with existing literature, particularly within the framework of Cognitive Behavioral Therapy (CBT), where one of its central tenets is the reformation of unhelpful thoughts into constructive statements and thought processes. The presence of self-talk across all participant categories underscores its intrinsic role in managing emotional responses and influencing behaviors. This convergence not only validates the importance of internal narratives in the context of HD but also resonates with the core principles of CBT, wherein the process of restructuring cognitions aligns with the broader endeavor to foster adaptive self-talk strategies for individuals navigating the challenges of hoarding behaviors and emotions (Chou et al., 2020; Sze & Wood, 2007).

A salient, final thread discerned throughout the diverse participant groups was the shared yearning for change and the pursuit of effective strategies to attain personal goals. While the specific objectives varied among the participant categories, the overarching aspiration for transformation remained consistent. Evident in multiple instances was the inclination of participants to seek advice and counsel from fellow members, while in other cases, the simple desire to make strides in their respective journeys was voiced. This observation stands in partial contrast to prevailing literature, which has noted instances of limited readiness or awareness to change, particularly among individuals grappling with HD (Frost et al., 2010). Nonetheless, literature underscores that the degree of desire for change can be significantly shaped by the therapeutic alliance—an essential common factor in effective psychological treatment (Wampold & Imel, 2015). The amalgamation of

understanding and collaboration between client and therapist amplifies client motivation and reinforces the pursuit of therapeutic outcomes. As revealed in research, therapists skilled in fostering rapport with their clients stand to effectively harness this innate desire for change (Finsrud et. al, 2022). As mentioned before, some therapists often struggle with their HD clients, and we unable to capitalize on this vital ingredient to therapeutic efficacy (Prochaska et al., 1992; Reynolds & Placido, 2020). Regardless, this recurrent theme attests to the resilience and unwavering determination exhibited by participants, underscoring their enduring perseverance amidst the distinct and ongoing challenges faced by individuals entangled in the complexities of HD and its impact on their immediate circles.

Differences Across the Data and Anomalies

In applying the AQAL framework (Wilber, 1995), distinct differences emerged concerning the internal focal points within the participant groups. Notably, those grappling with HD primarily aligned with the *I* quadrant. As revealed through the thematic analysis, conversations revolved around self and the multifaceted impact of the condition on their lives. In contrast, the themes expressed by children of parents with HD prominently resided in the *We* quadrant, highlighting their emphasis on interconnectedness and shared understanding. Friends and family members of individuals with HD exhibited a distinctive focus on the useful strategies for instigating positive change, aiming to cultivate a more supportive and comfortable environment for their dear ones—an inclination that steered them toward the *It* quadrant. Lastly, the public group's discussions fell within the *I* quadrant, reflecting their central concern of expressing opinions on the show's content and its resonance with their personal perspectives. While an argument might be made for the likelihood of distinct cohorts exhibiting differing focuses, another noteworthy revelation pertains to the notably low emphasis placed on the *Its* quadrant by all groups except the children of individuals with HD. As elucidated by Wilber (1995), this quadrant signifies the array of

systemic and institutional elements impacting both communities and the individuals within them. The notable, de-prioritization of this quadrant appears to align with the prevailing Western values of individualism and personal accountability—a stance that can inadvertently position the individual at the center of both affliction and recovery, as mentioned before (Bratiotis & Woody, 2020; Reynolds & Placido, 2020). The elevated awareness of this quadrant among the children of HD individuals stands in contrast, raising questions about the origins of their unique perspective. While speculation remains necessary, it is plausible that having inhabited this environment, their vantage point furnishes deeper insights into the contextual factors that either bolstered or hindered their individual struggles (Chabaud, 2011).

Another notable distinction observed in the data pertains to the variety of artifacts utilized and the frequency of their usage among the different participant groups. While it is acknowledged that distinct platforms offer differing sets of artifacts, it is worth noting that the opportunity to incorporate artifacts was present across all forums. As a case in point, the utilization of photographs was evident in both the group of individuals with HD and the children of those affected by HD. Within the former group, photographs displaying an individual's progress in cleaning, along with an organizational flow chart, emerged as common artifacts. Meanwhile, the latter group employed diagrams and stock images to visually communicate their ideas. A significant observation was the utilization of hashtags—an effective means for tracking content of interest—which was prevalent in both the children of individuals with HD and the public group. Distinctly, only the public group refrained from sharing external links to supplementary websites or resources. This characteristic aligns with their focus on discussing the show within the original topic thread, rather than proffering suggestions to fellow participants. Notably, the public group and the children of individuals

with HD group highlighted a higher frequency of emoticons and likes, harnessing these elements to convey their emotions and sentiments.

An intriguing outlier within the dataset surfaced within the friends and family members of individuals with HD group. This group notably reported encountering technical difficulties while attempting to post their content, an occurrence that held enough frequency to warrant its own distinct sub-theme. Although this issue pertains to the functionality of the platform, its effects are noteworthy. It is conceivable that this hurdle might have impacted the volume of artifacts contributed by this group. Furthermore, if these technical challenges occurred with regularity, it could have discouraged members from persistently attempting to upload artifacts. Such a phenomenon could potentially account for the diminished number of artifacts observed within this specific group.

In summary, this study delved into the intricate landscape of HD through a unique lens offered by digital ethnography. By closely examining the narratives and experiences shared across four distinct online groups—individuals with HD, children of those affected, friends and family members, and the broader public—we have unveiled a comprehensive tapestry of perspectives that enrich our understanding of this complex phenomenon. The thematic analysis of these digital spaces has illuminated the multifaceted dimensions of HD, capturing not only the personal struggles and challenges faced by those directly impacted but also the societal perceptions and attitudes that shape the discourse surrounding this condition. As we transition into the ensuing Discussion chapter, we will synthesize these insights to illuminate the broader implications of our findings, shedding light on potential avenues for intervention, support, and public awareness.

Conclusion

This investigation has produced a comprehensive and nuanced understanding of Hoarding Disorder (HD) through the exploration of four distinct participant groups. The

richness of the data sets, encompassing both verbal and visual representations, has illuminated the intricate dynamics within each group. While each group displayed its unique characteristics and concerns, there were striking similarities that transcended their individual experiences.

In the realm of personal introspection within the *I* AQALs quadrant, all groups grappled with their roles and positions within the context of HD. This process led to heightened self-awareness and a shared aspiration for personal growth and transformation. Within the *It* AQALs quadrant, the focus shifted towards exploring avenues for change, be it on an individual level or to support their loved ones affected by HD. These discussions held the promise of enhancing not only individual lives but also the quality of relationships within their respective spheres. In the *We* quadrant, a resounding commonality emerged, where all participant groups displayed a powerful sense of community and a genuine desire to connect, share experiences, and offer mutual support. This collective spirit underscored the importance of shared understanding and empathy within the HD community.

Finally, as we delved into the *Its* quadrant, our findings revealed a collective effort to perceive HD from a holistic perspective, acknowledging external factors that hindered progress. This broader outlook hinted at a shared commitment to addressing the disorder beyond its individual manifestations.

As we proceed to the Discussion section, our aim is to delve deeper into these findings, exploring their implications in the field of psychology. This investigation has not only enriched our comprehension of HD but also highlighted potential avenues for intervention, support, and further research. Through these insights, we aspire to contribute to the advancement of knowledge and the well-being of those impacted by HD.

Chapter 6: Discussion

In a world where the complexities of the human experience often intertwine with the digital landscape, this study delved into the depths of Hoarding Disorder (HD). Utilizing the method of digital ethnography, the journey led us to the virtual spaces of four distinct yet interconnected online groups: those directly affected by HD, the tenacious children of those affected, the steadfast friends and family standing by, and the voices from the broader public. In this chapter, I unravel the subtle threads that tie these digital communities together, revealing insights that transcend the pixels on our screens. This study has been founded on the critical research questions which sparked the curiosity and motivation of the investigation:

1. What is the nuance and flow of these online HD communities?

2. What are the key features of participation in online HD communities?

Equipped with the openness to the narratives shared and voices heard within these virtual spaces, I seek to illuminate the impact that such platforms have on lives touched by HD. The pursuit extends beyond the realm of data and statistics, reaching into the nuances of personal stories, quiet struggles, and moments of connection that transcend the boundaries of physical presence. The discussion will not only acknowledge the stories unveiled, but also recognize the limitations that were unavoidably present. It will close with the important, potential implications that could contribute to our understanding of HD and the intricate, interpersonal web of connections found within and around those involved.

Research Questions and Individuals with Hoarding Disorder

The thematic analysis of the conversations within the online groups revealed a landscape rich with shared experiences and emotional intricacies, illuminating the multifaceted nature of living with HD. Central to the discourse were focal points that revolved around strategies which could help individuals navigate the challenges posed by

HD. These included the emotional burdens felt by the members, the daily struggles that their items caused, and the fundamental human need for connection with others who understand their predicament. This thematic data aligned with the AQALs categorization, revealing a concentration of themes within the *I*, *It* and *We* quadrants. Moreover, the artefacts were also congruent with these findings, as they highlighted the individual and shared emotional connections, along with practical suggestions and personal successes.

Within this forum, a distinct atmosphere of safety and authenticity permeated the interactions. This environment nurtured a unique sharing space that not only acknowledged participants' individual struggles but also fostered an organic sense of support. In a stark departure from earlier research that portrayed individuals with HD as lacking insight into their condition (Frost & Hartl, 1996; Frost et al., 2010;), the participants of this investigation demonstrated that they were, in fact, aware of their struggles but less aware of ways to handle them. As the latter being a focus of conversation in the group, participants proceeded to provide supportive suggestions and experiences to address these struggles. This depth of mutual understanding through lived experiences enabled the participants to provide the patient, nurturing support not found in the counselling context, which was mentioned by the participants in the thematic analysis. As Collins (2018) and Paré (2013), therapists who can establish mutual understanding and co-create meaning with clients, therapeutic outcomes are more often achieved. One may argue that the lack of understanding in the therapeutic setting may account for therapeutic shortcomings with HD clients. As the literature shows, CBT is the main treatment method for HD, therefore, if CBT treatments are focusing on HD behaviors and less on emotional support and understanding, the high dropout rates and low adherence to intervention strategies, as mentioned by Frost et al. (2010), can be accounted for. As Tolin et al. (2012) notes, HD therapists often report frustrations and ruptures with their HD clients' lack on between-session compliance and are unable to co-create

understanding and meaning, further emphasizing the benefit such online groups bring to their participants, and the potential changes for therapeutic settings and interactions. Moreover, though the literature discusses the success rates CBT has for treatment of HD (Frost & Hartl, 1996), first-hand accounts of success stories are strikingly absent. For example, media images and case studies often present HD clients during their most extreme expression of HD behaviours, thus presenting HD as a drastic and almost uncurable disease. However, as demonstrated in the investigation, there are successes and many members gladly shared in the ways they were able to move towards personal progress. As the focus shifts away from the negative aspects of HD, towards positive triumph, further highlights the benefits of the groups and the lack of support found in other contexts.

In many ways, these online groups operate as virtual counseling spaces, where participants organically assume roles akin to counselors, nurturing empathy, understanding, and care. This evolution reflects the therapeutic alliance's core tenets: authentic empathy, collaborative meaning-making, and an absence of judgment (Laska & Wampold, 2014). As the participants embraced emotional understanding and expression, a notable divergence from the predominant cognitive-behavioral focus in HD therapy emerged (Beal, 2019; Mertens, 2020; Truscott, 2010). The participants' value placed on emotional resonance underlines the significance of incorporating emotional dimensions into therapeutic strategies, potentially offering a more comprehensive approach that resonates with individuals seeking a channel to navigate their emotional struggles alongside cognitive ones. This shift in emphasis holds implications not only for individuals' preferences but also for therapeutic strategies that can address the emotional, cognitive, and social dimensions of HD in tandem.

Research Questions and Children of Individual with Hoarding Disorder

Within this group, discussions and interactions focused on sharing the stories of their lived experiences and ongoing coping mechanisms to help ease their ever-present burdens.

This was supported by the emphasis of the *We* and *It* AQALs quadrant. Aligned with Chabaud's (2011) observations that children of individuals with HD often feel confused and emotionally abandoned, an undertone of emotional pain and anger permeated the group. The thematic analysis demonstrated how poignant vocabulary such as "*abuse*," "*neglect*," and "*imprisoned*" punctuated the conversations. Moreover, the artefacts revealed a depth of pain, frustration, and supportive care towards group members. This echoes an overarching ethos in alignment with extant research concerning family members of those afflicted by HD, as they too grapple with the emotional, financial, and physical ramifications of their loved ones' HD struggles (Bratiotis & Woody, 2020; Gargiulo et al., 2017; Tolin et al., 2008).

However, a palpable difference was noticed in this group, as the data sets bear testament to the profound emotional traumas these individuals have endured in their formative years and beyond. The literature's conspicuous silence surrounding this demographic echo the sidelining they experienced within their own families, with many members disclosing that they have chosen to sever ties with their parent(s) in a bid for emotional healing. This virtual haven thus becomes a sanctuary of validation, affording them a space of understanding unparalleled in their lives. By turning to the group and relating to one another, a virtual catharsis could occur, which may only be experienced with others of similar households and upbringings. Moreover, as demonstrated by the thematic analysis, members often discussed the diagnostic criteria, the inherent complexities of HD, and the gaps in both understanding and treatment. This was notable as this group had the highest discussion and artefact representation in the AQALs *Its* quadrant. Many participants called for a re-evaluation of these diagnostic features, as they expressed how many important aspects and impacts of HD were missed by the *DSM-5* and intervention strategies. With a depth of knowledge towards HD that can only result from a lifetime of first-hand experience, this group exposes a void in research and therapeutic support that specifically addresses the

distinctive challenges faced by this demographic and those with HD. The insights unearthed here underscore the importance of elevating their narratives, integrating their voices into the discourse surrounding HD, and fostering avenues of understanding that acknowledge the far-reaching implications of the disorder on family dynamics and emotional well-being.

Research Questions and Friends and Family Members of HD Individuals

Evidenced by the thematic analysis, this group stands out as a congregation of individuals bound by a resolute commitment to aiding their loved ones grappling with HD. This common purpose, driven by an ardent search for practical solutions, forms the bedrock of their interactions, which was supported by the AQALs placing most of the interactions in the *It* and *We* quadrants. Moreover, the artefacts proved the caring, supportive sentiments transmitted amongst the members.

Within this group, the participants fostered an atmosphere conducive to unreserved emotional expression, where they can openly articulate their sentiments regarding their relationships with both their HD-affected loved ones and the multifaceted challenges they face. This resonates with the prevailing literature, which underscores the emotional turmoil that often accompanies relationships entwined with HD (Bratiotis & Woody, 2020; Gargiulo et al., 2017; Tolin et al., 2008). The understanding fostered by this online forum accentuates a poignant realization: this group offers an opportunity for the members to have their emotional needs met, which may not be happening within the relationships with their HD-affected loved-ones. Moreover, if their loved ones are unable to recognize and/or articulate the intricacies of their HD struggles (Frost & Hartl, 1996; Frost et al., 2010;), this group may be an opportunity for more practical understanding and support. Notably, the discussions unveiled a recurring necessity among relatives to set up and enforce boundaries – a testament to the challenges of finding equilibrium in their roles as caregivers, supporters, and individuals with their own limits. Furthermore, the artefacts used within the group

conversations highlight an emotional landscape, formed of feelings of love, frustration, sadness, and confusion. This intricate mosaic reveals the multidimensional nature of their experiences, underscoring the undeniable need for more focused care and attention.

As the forum encourages the raw and genuine exchange of thoughts and feelings, it is evident that a subset of individuals impacted by HD could benefit from targeted care. For those whose loved one's struggle to fulfill their emotional needs, therapists emerge as potential allies in their journey. A reciprocal therapeutic alliance, brimming with authenticity and empathy, could offer a vital lifeline – a channel through which these individuals can navigate the intricacies of their roles, emotions, and aspirations while nurturing their own well-being in parallel with their caregiving responsibilities (Laska & Wampold, 2014). Moreover, couples/group therapies could be a helpful supplement to individual therapy, to enhance communication and understanding between loved ones. This way, the onus of change and responsibility is not placed entirely on the individual, as is often the case in western-based understanding of disease and cure (Bratiotis & Woody, 2020; Reynolds & Placido, 2020). As this investigation has demonstrated, HD affects the ecological systems surrounding the individual. Therefore, affording space to all voices involved can enhances the inclusivity in understanding the condition and the ways to incorporate more culturally responsive and effective treatment (Collins, 2018; Paniagua, 2018; Paré, 2013; Smart & Smart, 1997).

Research Questions and the General Public

Within this online group, the thematic analysis revealed an overarching negative focus, as participants dissect and analyze the HD-focused television shows. With most themes falling into the AQALs *I* and *We* quadrants, the camaraderie is outlined with sharper edges, as dissenting opinions and pointed disagreements color the interactions. Despite the participants' comfort in sharing their viewpoints, the ambience remains notably less nurturing

compared to the other groups. This resonates with the existing literature that underscores how individuals untouched by a particular condition often exhibit tendencies toward stigma and *othering* when confronted with those grappling with it (Corrigan & Watson, 2002).

Conversely, the thematic analysis also revealed that beneath the main, negative focus, a positive and supportive underlay exists. This was demonstrated by positive comments towards the content and participants on the programs. Given that the members of this group assume a passive observer role while commenting on television shows, their internal reflections and subsequent shared interactions naturally take precedence. Empathy begins to blossom within this domain, although the depth of connection remains shallower compared to the other groups. This nuanced interweaving of themes underscores the multifaceted nature of the human response, reflecting the spectrum of reactions HD invokes.

Crucially, the polarized focus within the group crystallizes a pivotal juncture in the broader understanding and acceptance of HD within society. The stark divide – oscillating between negative criticism and positive resonance – mirrors the variance in public perception and acknowledgment. In a landscape where these shows often prioritize entertainment over education, an opportunity arises to recalibrate their objectives. By pivoting towards a more informative and empathetic stance, these shows could facilitate a shift in public perception, culminating in a more profound and compassionate understanding of HD. To facilitate such a shift in media portrayals, advocates, such as counsellors, possess the power to drive social justice both within and beyond therapy sessions (Collins, 2018). By taking proactive steps, therapists can make a significant impact. Engaging with media to create new, educational shows could promote a more accurate understanding of HD's challenges. This effort seeks to amplify the voices of our clients and community members, fostering an environment of acceptance and support, rather than judgment and criticism. As the literature indicates, HD affects the grander community (Frost et al., 2000). Therefore, by showcasing the ways HD

impacts society and the ways other members can positively involve themselves in change, we can collectively move towards a more just and empathetic society.

Implications of Research

The foundations of the implications of this study rest on the notion of resonance, which Small and Calarco (2022), describe as an understanding of participants' beliefs to understand the work people do to resolve the everyday tensions produced by a group's culture. By adopting an insider's approach to HD, regardless of one's position towards the condition, an individual may come to understand the first-hand accounts of those experiencing the condition daily. Through this awareness, this investigation holds significant implications that can reshape our understanding of HD and its treatment approach. These implications primarily revolve around the therapeutic interventions used, the role of counselors, and how HD is portrayed and perceived.

As mentioned previously, from the clinical, outsider's perspective, HD has been seen as a mental disease, illustrated by a myriad of diagnostic criteria; categorizing the degree of affliction of patients based on their presenting concerns. As a result, the professional community has gravely overlooked the ethical foundations, which the therapeutic profession has been founded upon – respect for the dignity of all persons (Canadian Psychological Association, 2017). One may argue that distilling the human experience of vulnerable people into the categorization of symptoms, without accounting for the narratives that highlight the tribulations faced by these individuals, lacks the professional empathy needed to establish the safe and equalitarian relationship essential to health and healing (Paré, 2013). As a result, intervention strategies, such as CBT, have emerged as the main approach to HD treatment. Whilst CBT excels at strategizing change patterns and addressing obstructive thoughts and feelings related to HD (Steketee et al., 2010), its concentration on thoughts and behaviors may inadvertently neglect essential emotional exploration. The common yearning to

emotionally connect and share experiences, which was found across the groups, suggests an emphasis on emotional connection rather than purely logical strategies. The group members' willingness to express their inner thoughts could imply an absence of emotional expression and understanding outside of the group. Hence, a stronger focus on building the therapeutic alliance and nurturing emotional understanding could greatly benefit those directly affected by HD, which calls for a change in the therapeutic alliance. As described in the study, many of the individuals' voiced concerns of disconnect between themselves and their counsellor, often highlighting that they felt misunderstood during sessions. This is also evidence in the research regarding counsellor's distress when working with HD clients (Holden, et al., 2019; Tolin et al., 2012). Therefore, this study highlights the importance of co-creating meaning with clients in order to foster a collaborative therapeutic setting to attain treatment goals (Paré, 2013).

Aside from the narratives based on individuals with HD, an important implication of this study stems from the insights derived from the experiences of children of individuals with HD. Clearly, emotional pain, neglect, and anger underlie their narratives. Their alignment with literature regarding low insight in those with HD (Frost & Hartl, 1996), highlights an overlooked aspect: the emotional needs of children and potential family members. Isolation and shame, often reported by those with HD (Frost et al., 2010), might stem from the distancing of children and friends/family members. To address this gap, greater understanding is necessary, along with urgent steps like individual counselling for children and friends/family members of individuals with HD, as well as family/group counselling. Moreover, connecting individuals who have shared experiences with HD can prove beneficial to their individual healing, along with the relationships of their loved-ones. Through the support of therapeutic alliances, these avenues offer the opportunity to share experiences, reconnect with loved ones, and mend the divisions that have emerged.

A third implication surfaces in the roles of therapists and community members in understanding our friends, family, and neighbors. Television networks exploiting mental illness for entertainment and profit perpetuate stigma. As many of these accounts are exaggerated accounts aimed at ratings, the real individuals behind HD are marginalized for the purposes of entertainment. Professionally, our silence towards such forms of exploitation inadvertently adds to this harmful narrative, causing ongoing friction and polarization amongst those with and without psychological struggles. During my academic journey, the concept of enacting social change seemed distant and intangible. However, delving into this investigation and listening to the voices of these communities has illuminated how seemingly small actions, like online forums, can remarkably support and assist. It has also underscored the far-reaching influence of significant entities, like popular television shows with record-breaking viewership. Efforts such as petitioning networks can steer the narrative, along with fostering informative spaces to distinguish between entertainment and reality. We, as individuals, can also wield personal accountability in our media consumption. Perhaps if ratings decrease, so will the shows which are perpetuating misunderstandings. Change is attainable, provided we take action by allowing the brave voices of the HD community to be shared, embraced and understood with compassion and empathy. Though the limitations of this study follow, this investigation is the beginning of a step towards greater understanding from the individuals' perspective, which aims to promote client autonomy, recognition and acceptance both in and out of the therapeutic setting.

Limitations

As the study positioned me as a passive observer within the groups, a primary limitation arises from the absence of direct connection with participants. Therefore, precise knowledge of the participants' relationships with HD creates a gap in validity. While one may assume the participants would engage in a group relevant to their interests/needs, the validity

gap introduces potential data inaccuracies. To address this, future investigations could incorporate a process enabling researchers and participants to openly discuss their affiliation with the condition. Additionally, the inability to use identifiers in the dataset restricted the comprehensive sharing of participants' stories. This limitation hindered the portrayal of their struggles and achievements in their full richness. To address this gap, future research is encouraged to foster participant connections, allowing their stories to authentically represent the individuals behind them. Cultural awareness of participants and their contributions represents another limitation. All groups displayed a diminished emphasis on the *Its* AQALs quadrant, reflecting a tendency to overlook systemic factors. This inclination aligns with Western individualism. Yet, participants' cultural backgrounds and how these shaped their connections to HD remain unknown. Conducted in English, the study's assumptions about participant language backgrounds might inadvertently reinforce Western-centric interpretations of mental conditions (Reynolds & Placido, 2020). This underlines the need to better comprehend participants' backgrounds and values. Future research could benefit from exploring various cultural contexts by utilizing forums from different countries. This approach would enrich datasets, deepen our comprehension of HD, and cultivate a more inclusive understanding. Moreover, as this study was conducted using Internet-based discussion forums, another limitation in the study surrounding the participants' socio-economic status and Internet-user knowledge/ability exists. This limitation excludes a population of individuals who are lacking in computer/Internet access, and knowledge of traversing and interacting within the groups. To address this, future studies could include other offline populations, thereby enriching the data set. Finally, a degree of insight towards HD assumingly exists within the population of participants, which is contrary to the literature highlighting individuals with HD to have low insight towards the condition (American Psychiatric Association, 2013). Therefore, the participants in this study may represent a

unique cluster of higher-functioning individuals. To address this, more diverse participant groups from different contexts may be used to better capture the nature of individuals affected by HD.

Chapter 7: Conclusion

In the pursuit of unraveling the intricate tapestry of HD, this study employed the lens of digital ethnography to illuminate the nuanced interactions within four distinct online groups. The primary objective was to gain an insider's perspective, shedding the traditional outsider's view, and to decipher the profound impact of group participation on the lives of those directly affected. This journey has offered an exceptional opportunity to traverse alongside individuals grappling with this condition, while also deepening our insights into the lives of their resilient children, steadfast friends and family, and the surrounding communities.

The canvas woven by the data is a spectrum of understanding and enrichment, revealing connections and evoking empathy. It is adorned with hues of struggle, pain, anger, and doubt, capturing the complexity of the human experience. Beneath this intricate mosaic, a broader portrait emerges—one that celebrates the innate beauty of the human spirit, ceaselessly evolving and questing for positive growth and transformation. Amidst these threads of experience, the online communities emerge as sanctuaries, providing refuge, care, and understanding through the compassionate presence of their members. In this light, as therapists, we are reminded of the potential of our therapeutic alliance. It is a realm where we can not only nurture an unwavering sense of care and concern but also cultivate an authentic desire to comprehend and support those navigating the contours of HD at their own pace.

This investigation underscores the need for an ongoing journey of understanding and progress. It serves as a vital point of departure—a fertile soil from which growth can blossom. It kindles a beacon of change and hope, emphasizing the importance of seeing individuals beyond the confines of diagnostic criteria. Ultimately, this study champions the idea that every individual has a unique narrative and a distinctive journey, deserving of recognition, understanding, and a chance to thrive.

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Appendix A
Certificate of Completion of Tri-Council Research Ethics Course

PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Tracy Quayat

has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)

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Date of Issue: **8 October, 2021**

Appendix B
Reflexive Journal

Journal Entry #1

Today marks the beginning of an extraordinary journey as I delve into the world of Hoarding Disorder (HD) for my thesis. This disorder, often misunderstood and overlooked, affects not only individuals but also their families and communities. As I embark on this research, I find myself drawn to the idea of including different perspectives to gain a comprehensive understanding of the complexities surrounding HD.

Firstly, I believe it is essential to include the voices of those directly affected by HD—individuals who struggle with the disorder themselves. Their experiences, challenges, and coping mechanisms provide invaluable insights into the psychological and emotional aspects of hoarding. By giving them a platform to share their stories, I hope to promote empathy and understanding, ultimately leading to better-informed interventions. Secondly, I must not forget to involve the children of those grappling with HD. Growing up in such an environment can leave a lasting impact on their lives. Understanding their perspectives may shed light on the long-term effects and guide the development of support systems tailored to their needs.

Equally important are the family members of individuals with HD. Their role in the hoarding dynamic is intricate and often fraught with emotional struggles. By including their experiences, I hope to highlight the challenges they face and foster support networks that address their well-being as well. Lastly, I consider the general public's perceptions of hoarding. Including their opinions and knowledge about the disorder will help identify misconceptions, raise awareness, and reduce the stigma surrounding HD. This can lead to increased support and resources for those affected.

Regarding data collection, the idea of utilizing multiple platforms resonates with me. Employing a diverse range of platforms, such as interviews, surveys, online forums, and focus groups, would enrich the data pool significantly. Each avenue provides unique perspectives and allows for triangulation, enhancing the credibility of my findings. While using a single platform might seem convenient, it could limit the richness and depth of the data gathered. Embracing various platforms might initially appear challenging to manage, but it will lead to a more comprehensive understanding of the multifaceted aspects of HD.

Diverse data can help identify patterns, discrepancies, and nuances that might otherwise be overlooked, making the extra effort worthwhile.

As I move forward, I am excited to embark on this interdisciplinary research journey, hoping to shine a light on Hoarding Disorder and contribute to a better-informed approach towards supporting those affected by it.

Journal Entry #2

As my research into Hoarding Disorder (HD) progresses, I've come to a realization that not everyone I want to include in the study is formally diagnosed with HD. This observation has opened my eyes to the complexities of studying a disorder that is not always clearly delineated and can manifest in various ways among different individuals. While I had initially planned to include various groups of people, including individuals with diagnosed HD, children of those with HD, family members, and the general public, it has become evident that some participants may not possess an official diagnosis. This raises challenges in accurately identifying and classifying individuals for the study, as the lack of formal diagnosis could potentially impact their perspectives and experiences.

To address this limitation, I've decided to approach the situation with sensitivity and empathy. While I won't have the certainty of a formal diagnosis for some participants, I will assume, for intents and purposes, that they are individuals affected by HD. By adopting this approach, I hope to ensure that the voices of those who may be struggling with HD-related challenges are heard and acknowledged. However, I am fully aware of the importance of addressing this issue responsibly. I will discuss this matter candidly with my supervisors, seeking their guidance on how to approach the wording and classification of these individuals in the research. Honesty and transparency will be critical as I navigate this aspect of the study, and I aim to document this potential limitation in the research report's limitations section.

As I move forward, I recognize that the inclusion of participants without formal diagnoses may bring added complexity, but it also presents an opportunity to shed light on the less-explored aspects of hoarding behavior and its impact. My commitment remains to conduct thorough research that fosters understanding, empathy, and effective support for all individuals involved in the context of HD.

Journal Entry #3

As I venture deeper into my research on Hoarding Disorder (HD), a new challenge has arisen – determining the number of posts I will include from each category. While I strive for a balanced representation to ensure a comprehensive analysis, I am facing difficulties in finding an equal number of posts and comments for all categories. My intention was to collect a sufficient number of posts from individuals with HD, children of those with HD, family members, and the general public to gain diverse perspectives. However, the reality of obtaining the same length of posts and the same number of comments across all categories has proven to be more complex than anticipated.

To strike a balance, I find myself grappling with the dilemma of whether to prioritize quantity or to emphasize the quality and depth of the responses. I am aware that each category contributes unique insights, and an unequal representation might potentially skew the findings. After much consideration, I have decided to take ten comments and ten thread replies or comments from each category. While it may not be a perfectly equal balance, this approach will still offer a substantial dataset for analysis. It allows me to explore a range of viewpoints while acknowledging the inherent challenges in obtaining identical quantities from each group.

Nevertheless, I understand the importance of discussing this issue openly with my supervisors. Seeking their input will be valuable, as they can provide guidance on how to manage any disparities in data representation. By addressing this concern transparently, I aim to ensure the credibility and rigor of my research. As I navigate this stage of data collection, I am reminded that research is a dynamic process. Adapting to unforeseen challenges is part of the journey. My commitment remains to approach this study with integrity and diligence, acknowledging any limitations that may arise, and striving to present a comprehensive and thoughtful exploration of Hoarding Disorder and its impacts.

Journal Entry #4

Today marks a significant milestone in my research on Hoarding Disorder (HD) as I have successfully gathered all the posts and labeled them in a comprehensive catalog. The compilation of these valuable insights from individuals with HD, children of those with HD, family members, and the general public fills me with a sense of purpose and responsibility.

To safeguard the integrity of the data, I made the careful decision to take screenshots and record the posts instead of solely relying on the original threads. This proactive measure

ensures that even if the original threads are deleted or modified, I have a secure record of the information shared. Preserving these accounts is crucial to maintaining the validity and reliability of my research findings. However, in doing so, I must remain acutely aware of the privacy concerns surrounding the data I've collected. Anonymity and confidentiality are paramount, and I am committed to adhering to ethical guidelines throughout this process. To protect the identities of the participants, I have diligently removed any identifying markers such as usernames, profile pictures, and any other personal details from the screenshots and recordings.

As I progress, I am exploring the best practices for data storage. Ensuring that these files are kept secure and inaccessible to unauthorized individuals is of utmost importance. I will implement encryption and password protection to safeguard the sensitive information contained within. I cannot stress enough the significance of maintaining the privacy and confidentiality of those who entrusted me with their experiences. The responsibility lies with me to treat this data with the utmost respect and care. By upholding the ethical principles of research, I strive to foster trust and respect among all participants.

As I move forward, I will continue to be vigilant in protecting the privacy of the participants and maintaining the integrity of the data. It is my hope that this research will contribute to a deeper understanding of HD and pave the way for more compassionate and effective support for those impacted by this disorder.

Journal Entry #5

I can hardly contain my excitement as I've now embarked on the coding process for my research on Hoarding Disorder (HD). It's exhilarating to immerse myself in the narratives of the participants and explore the intricacies of their worlds and experiences. Each post I analyze feels like a window into their lives, shedding light on the complexities of HD from unique perspectives. Getting to 'know' the participants through their words has been an eye-opening journey. Their stories, emotions, and struggles resonate deeply with me. As I read their accounts, I find myself developing a profound sense of empathy and understanding for the challenges they face daily. I am grateful for this opportunity to engage with their narratives, and I hope that my analysis will do justice to their voices and experiences.
The coding process, while exhilarating, also comes with its fair share of challenges. Being relatively new to this aspect of research, I find myself occasionally overwhelmed by the amount of data to process. The responsibility to accurately identify and categorize the themes and patterns that emerge from the narratives is both thrilling and daunting. To ensure rigor

and reliability, I have adopted the practice of double coding. This involves revisiting the data at a later time to see if I arrive at the same codes consistently. While it demands more time and effort, it provides me with confidence in the credibility of my findings. The iterative nature of coding allows for a deeper exploration of the data, enabling me to capture the nuances and subtleties that might have been overlooked in initial analyses.

I am committed to giving my best in this coding process, recognizing that it is an essential step in making sense of the vast amount of qualitative data I've collected. It is both a humbling and empowering experience to be entrusted with these personal stories, and I am dedicated to honoring their voices with integrity and respect. As I continue coding, I remind myself to approach the process with an open mind and remain receptive to the unexpected insights that may emerge. I am eager to uncover the threads that connect these narratives and contribute to a deeper understanding of HD, ultimately paving the way for more compassionate and effective support for those affected by this challenging disorder.

Journal Entry #6

As I progress further into my research journey on Hoarding Disorder (HD), I find myself grappling with the use of NVivo software to manage the coding process. While NVivo offers valuable tools for qualitative analysis, I can't help but feel that relying solely on the software might inadvertently distance me from the essence of the data and the participants' stories.

Throughout this research project, I have held the belief that honoring the "insiders' understanding" of HD is paramount. I want to remain deeply connected to the narratives, to truly grasp the lived experiences of those affected by HD. However, using software creates a sort of intermediary layer between me and the data, making me wonder if I might lose some of the rich nuances and subtleties that emerge in the narratives.

While NVivo certainly provides efficiency and organization, it also seems to bring with it the risk of potential detachment from the raw experiences conveyed in the participants' posts. I find myself contemplating whether the software could inadvertently filter or shape my analysis in unintended ways. With these considerations in mind, I have decided to prioritize my direct involvement in the coding and analysis process. Staying as close to the data as possible aligns with my values and commitment to preserving the authenticity of the participants' stories. By manually immersing myself in the narratives, I can maintain a personal connection with the data, allowing me to notice the intricacies and complexities that might be obscured by relying solely on automated software.

This decision may require more time and effort, but I believe it is a worthwhile investment in conducting ethically responsible research. My goal is to honor the participants' voices, to respect their courage in sharing their experiences, and to ensure that the findings genuinely reflect their truths. As I move forward, I will proceed with a combination of careful manual coding and select use of NVivo for organizational purposes. This way, I can maintain a balance between efficiency and the intimate connection to the data that is vital for this study. By doing so, I hope to generate meaningful insights and contribute to the understanding and support of those impacted by HD.

Journal Entry #7

This research journey on Hoarding Disorder (HD) has been profoundly rewarding, as I delve deeper into the first-person experiences of individuals with HD, their friends and family members, and the perspectives of the general public. Each day, I feel like I'm unlocking hidden doors to understanding the intricacies of this complex disorder, and I am humbled by the courage and resilience of the participants who have entrusted me with their stories.

Understanding the first-person experiences of individuals with HD has been a transformative aspect of this project. Through their narratives, I've gained a more profound insight into the emotional turmoil, daily challenges, and coping mechanisms they employ to navigate their lives. Their stories have humanized the disorder, dispelled misconceptions and enabling me to view HD with greater empathy and understanding. Equally valuable has been exploring the experiences of children of those with HD and family members. Hearing their accounts has highlighted the far-reaching impact of HD on familial relationships, mental well-being, and the dynamics within households. Their stories underscore the significance of addressing HD as a family concern, necessitating a support system that extends beyond the individual with the disorder.

Gaining insights into the general public's perspectives has also been eye-opening. It revealed a range of beliefs, misconceptions, and attitudes towards hoarding, some influenced by media portrayals. Unfortunately, the negative remarks and sensationalized depictions in the media have perpetuated stigma and further alienated those with HD. This revelation has awakened a sense of concern within me, recognizing the need for social justice work in advocating for a more compassionate and accurate portrayal of hoarding. Moving forward, I am contemplating taking personal initiatives to contribute to this social justice effort. I feel compelled to challenge the damaging narratives in the media by petitioning for shows and documentaries

to adopt a more empathetic and informative perspective on hoarding. Additionally, I am considering creating a platform where individuals with HD can share their experiences in a supportive and non-judgmental environment. Such a forum could not only foster understanding but also provide a sense of community and empowerment for those impacted by HD.

This research journey has been an extraordinary opportunity to explore the world of HD from various angles, gaining invaluable insights into the lives of those affected. As I conclude this project, I carry a profound sense of responsibility to disseminate the findings responsibly, promoting awareness, empathy, and advocating for a more compassionate and inclusive society for individuals with HD and their loved ones.

Journal Entry #8

As I delve deeper into the coding process for my research on Hoarding Disorder (HD), I have encountered an intriguing challenge - the presence of artifacts like pictures and emojis in the participants' posts. While these artifacts offer an additional layer of insight into their experiences, they also introduce an element of subjectivity in the interpretation.

Pictures are indeed worth a thousand words, and they can provide a glimpse into the physical environment of individuals with HD. The visual representation of clutter and the living conditions helps me grasp the severity of the disorder. However, understanding the full context and meaning behind these images is not always clear. Deciphering the emotions or thoughts associated with these pictures solely from passive observation poses a challenge. Similarly, emojis, while expressive, leave room for interpretation. Emojis can convey emotions, reactions, or even humor, but the true intent behind their use may not be evident without direct interaction or follow-up questions. The meaning behind an emoji can be context-dependent, and as a researcher, I must be cautious not to jump to conclusions about the participants' emotions solely based on emojis.

This aspect of the coding process highlights a potential limitation in my research. While I strive to capture the essence of the participants' experiences as accurately as possible, passive observation may miss critical information that could otherwise be clarified through interactive methods. Engaging in dialogue with participants could provide a more nuanced understanding of the artifacts and aid in deciphering their true intentions. In my upcoming discussions with my supervisor and colleagues, I intend to address this challenge transparently and explore potential strategies for mitigating the limitations. Engaging in

interactive interviews or follow-up questions with participants might be a viable approach to gaining a deeper understanding of the artifacts and their significance.

Furthermore, this aspect of the research sparks an interesting possibility for future investigation. A research project dedicated to exploring the communication patterns of individuals with HD, including the use of artifacts like pictures and emojis, could shed light on the intricacies of their expressions and provide valuable insights into their experiences. As I continue with my current research, I am committed to being mindful of these limitations while striving to maintain the highest level of rigor and sensitivity in my analysis. Unraveling the stories hidden within the artifacts requires a delicate balance of objective analysis and a deep appreciation for the complexities of human expression.

Journal Entry #9

As I near the conclusion of my research on Hoarding Disorder (HD), a new challenge lies ahead - determining the best way to showcase and display the results. The thought of presenting the data in a clear, meaningful, and accessible manner is both exciting and daunting, especially since this is my first time undertaking such a task.

One option that comes to mind is using graphs and scatter plots to visualize the patterns and trends that emerge from the coding process. Graphs can be powerful tools to illustrate the prevalence of specific themes or the relationships between different variables. However, I am grappling with the question of whether graphs alone will be sufficient to truly convey the depth and complexity of the participants' experiences. The priority lies in ensuring that the results are accessible not only to academic peers and professionals but also to the general public or lay-persons. I remember a valuable lesson from one of my courses about the importance of making research findings comprehensible and meaningful to a broader audience. It is crucial to avoid overly technical jargon or complicated visualizations that might alienate non-experts.

As I ponder over these considerations, I am eager to seek guidance from my supervisor. Their expertise and experience will be instrumental in helping me identify the most effective and inclusive way to present the results. I am confident that they will offer valuable insights into selecting appropriate visual representations that strike a balance between clarity and accessibility. One idea that intrigues me is incorporating qualitative excerpts alongside the graphs. This approach could humanize the data, allowing readers to connect with the participants' experiences on a more personal level. By combining quantitative data with

qualitative quotes, I hope to create a comprehensive narrative that conveys both the statistical findings and the lived realities of individuals with HD and their loved ones.

Ultimately, my goal is to ensure that the research findings resonate with a diverse audience, from fellow researchers to those directly impacted by HD. I want to present the results in a way that honors the participants' stories and provides meaningful insights that can guide future interventions and support systems. As I progress toward presenting the results, I will keep the principle of accessibility at the forefront of my mind. By striving to communicate the findings in a clear, approachable, and compassionate manner, I hope to contribute to a broader understanding of Hoarding Disorder and foster support and empathy for those affected by this challenging condition.

Journal Entry #10

As I wrap up the data analysis section of my research on Hoarding Disorder (HD), a strange mix of satisfaction and doubt fills me. On one hand, I feel a sense of accomplishment, knowing that the hard part of gathering, coding, and analyzing the data is behind me. On the other hand, doubt lingers as I recognize that I am still an emerging researcher, and this is my first time undertaking a project of this magnitude entirely on my own.

Despite the uncertainties, I am proud of the effort and dedication I have poured into this research. The journey has been a rollercoaster of emotions, from excitement and curiosity to challenges and moments of self-doubt. But through it all, the courage and openness of the participants have been a guiding light, inspiring me to push forward with determination. As I reflect on the data analysis process, one unique approach that stands out is the AQALS method. Inspired by Ken Wilbur's integral theory, the AQALS framework represents the data within four quadrants—individual, collective, individualistic, and holistic perspectives. This representation offers an interesting Eastern perspective on the data, acknowledging the importance of considering cultural contexts when exploring the complexities of HD.

Indeed, there is an urgent need for a more holistic understanding of conditions like HD, particularly as Western diagnostic tools, such as the DSM, are often applied cross-culturally without adequate consideration of cultural differences. The underrepresentation of Eastern and collectivistic cultures in diagnoses underscores the importance of incorporating diverse cultural lenses when studying and addressing mental health issues. As I move forward with the interpretation and discussion of the findings, I will be mindful of the implications of culture on HD and how the disorder may manifest differently across various cultural contexts.

By recognizing these nuances, I hope to contribute to a more comprehensive and inclusive understanding of HD that acknowledges the cultural dimensions impacting the experiences of those affected.

Despite the sense of accomplishment, I remain aware of the limitations inherent in my research. Being a solo researcher, I have missed the collaborative dynamics that come with working in a team. Peer feedback and constructive criticism can be invaluable in refining the research and ensuring its validity. However, I am grateful for the support of my supervisor, who has been a pillar of guidance throughout this journey. As I finalize the analysis, I cannot help but wonder how this research might be of help to others. My hope is that the findings will contribute to a deeper understanding of HD, prompting compassionate and effective interventions for those impacted by the disorder. By shedding light on the experiences of individuals with HD, their families, and the general public, I aspire to spark conversations that lead to increased empathy and support.

As I conclude this phase of my research, I recognize that the road ahead holds many possibilities. There are still chapters to be written, discussions to be had, and avenues for further exploration. My passion for this topic remains steadfast, and I look forward to sharing the results with the academic community, mental health professionals, and individuals seeking insights into the world of Hoarding Disorder. I am eager to contribute to the growing body of knowledge surrounding HD, and I am hopeful that my work will have a positive impact on the lives of those affected by this challenging condition.

Journal Entry #11

As I transition into the write-up phase of my research on Hoarding Disorder (HD), I find myself at the starting point - crafting the introduction. While I aim to present myself as knowledgeable and intelligent, I also strive to maintain authenticity and allow my true self to shine through the words on paper.

These reflections have become more prominent in my mind since I started my practicum and began using Internal Family Systems (IFS) therapy, drawing inspiration from the work of Dick Schwartz. The concept of 'parts' within me has allowed me to become more aware of the different aspects of myself - the ambitious researcher, the empathetic listener, and the vulnerable human behind the project. In writing the introduction, I want to strike a balance. On one hand, I want to convey my expertise and competence in the subject matter, providing a strong foundation for the research that follows. On the other hand, I don't want my presentation to overshadow the personal journey and growth that this project has offered me.

Honoring my experiences and vulnerabilities, I hope to create an introduction that is both professional and genuine.

However, I must admit that I am currently experiencing a bit of writer's block. The pressure to craft the perfect introduction, coupled with the emotional weight of the research journey, feels overwhelming. Recognizing the importance of self-care, I have decided to step away from the project for a little while. I plan to engage in activities that replenish my energy and creativity. Spending time with loved ones, engaging in mindfulness practices, and immersing myself in hobbies that bring me joy will be instrumental in finding clarity and renewed motivation. During this break, I will allow the thoughts and ideas to marinate, trusting that the inspiration will flow naturally when the time is right. Sometimes, taking a step back can lead to breakthroughs and fresh perspectives.

As I continue this write-up phase, I will strive to weave together my academic knowledge, research findings, and personal reflections in a cohesive narrative. My intention is to share not just the research outcomes but also the valuable insights and growth that have emerged through this process.

By embracing both the researcher and the human behind the research, I hope to create a meaningful and impactful document that sheds light on the complexities of Hoarding Disorder and contributes to greater understanding and compassion for those affected by this condition. The journey is far from over, and I look forward to the next chapter of this endeavor, filled with new insights and opportunities for growth.

Journal Entry #12

As I sit down to write this entry, a sense of discouragement weighs heavy on my mind. The practicum experience I've embarked upon has been incredibly rewarding, as I take on clients and delve into the world of therapy. However, amidst the excitement and fulfillment, I find myself grappling with anxiety as I realize how much time has passed without progress on my thesis.

The practicum has been an invaluable learning experience, offering opportunities to connect with clients, apply therapeutic techniques, and witness transformative growth. Each session brings new challenges and insights, reminding me why I chose this path in the first place. However, the demanding schedule and emotional investment in clients have left little time and mental space to focus on my thesis. The knowledge that the clock is ticking, and the deadline for my thesis is looming, fills me with apprehension. Time is a finite resource, and I

feel a weight on my shoulders, knowing that I have not made significant progress on my research while juggling the demands of the practicum.

Though I wish I had the luxury of dedicating more hours to my thesis, I also recognize the importance of being present and fully engaged with my clients during this practicum. The connection and growth that occurs within the therapy room are precious, and I don't want to undermine their significance. In navigating this challenging period, I am learning the importance of balance and self-compassion. I must be gentle with myself and acknowledge that I am in the midst of a significant learning curve with the practicum. It's okay to feel a bit overwhelmed and to need time to adjust to this new experience.

During the limited time I do have, I strive to make the most of it by being intentional and focused. Setting small, achievable goals for my thesis and dedicating specific blocks of time to work on it, even if brief, can make a difference. Celebrating each bit of progress, no matter how small, helps keep me motivated and reminds me that I am making strides.
As I navigate this juncture, I remind myself that it's okay to feel anxious and uncertain. Embracing the ebb and flow of life, and the different roles I'm currently fulfilling, allows me to cultivate a more holistic perspective. In the grand scheme of things, both the practicum and the thesis are essential stepping stones on my journey as a researcher and therapist.
As I persevere through this challenging period, I know that growth is happening both professionally and personally. This time of learning and transition will pass, and I will emerge with new insights and a deeper understanding of myself and the fields I am passionate about. I will continue to navigate this balancing act with resilience and determination, trusting that the path forward will become clearer with each step I take.

Journal Entry #13

Today brought an unexpected turn of events that has left me feeling anxious and a little lost. My supervisor, who is a leading specialist in Hoarding Disorder (HD), has suddenly fallen ill. The news has shaken me, as I heavily rely on their expertise and guidance for my research. Having worked closely with my supervisor throughout this journey, I've come to value their insights and wisdom. They have been a pillar of support, offering clarity and direction in navigating the complexities of HD. Their absence leaves a void that is hard to fill, and I find myself grappling with uncertainty about how to proceed. Thankfully, I am not entirely alone in this situation. I have a second supervisor who has also been involved in overseeing my research. While I am grateful for their presence, I cannot deny the unease I feel without the guidance of my primary supervisor, who is a true HD specialist.

At times like this, I realize the importance of perseverance. Though I may feel shaken and uncertain, I must summon the determination to continue moving forward. This is a critical juncture in my research, and I cannot afford to lose momentum. There are participants counting on me to honor their stories and present their experiences in a meaningful way. In this moment of uncertainty, I am reminded of the resilience that has brought me to this point. The passion and dedication that drove me to undertake this research project are still within me. It is time to lean into that determination and forge ahead, even in the face of challenges.

I will reach out to my second supervisor for guidance and support during this time. Their expertise may not be specific to HD, but I know that their insights will be valuable nonetheless. Together, we can brainstorm strategies for navigating this period and ensure that the research continues with integrity.

In times of difficulty, it's essential to draw strength from the support systems that surround me. I have colleagues, friends, and mentors who I can lean on for advice and encouragement. Their belief in me fuels my own belief in myself, reminding me that I am capable of overcoming obstacles.

As I persevere through this uncertainty, I am committed to honoring my primary supervisor's knowledge and expertise by applying the lessons they have imparted to my research. Though they may not be able to guide me directly at this moment, I will carry their insights with me as I continue to explore the world of Hoarding Disorder.

While it may feel like I am navigating uncharted territory, I know that I have the strength and determination to face whatever challenges lie ahead. I will forge ahead with a renewed sense of purpose, trusting that this journey will lead me to new insights, growth, and a deeper understanding of the complexities of HD.

Journal Entry #14

Today, I'm filled with a sense of accomplishment and relief. After days of hesitation, I have finally started working on the introduction for my research on Hoarding Disorder. At first, I felt that my initial words lacked my authentic voice, and I became tangled in the grip of perfectionism. The fear of not getting everything perfect on the first go hindered my progress.

Being a perfectionist can be both a blessing and a curse. While it drives me to strive for excellence, it also creates mental friction that can make even starting a piece of writing seem

daunting. However, I've realized that I must shift away from this mindset and give myself permission to write freely.

So, I've decided to embrace the concept of permission over perfection. I'm allowing myself to write whatever thoughts come to mind without self-judgment or the need for everything to be flawless from the start. The beauty of writing is that it can be shaped and molded during the editing process, which is exactly why I need to get these initial ideas down on paper.

The introduction sets the stage for the entire thesis, and I want it to be an honest reflection of my journey and my passion for this research. I must trust in my abilities as a researcher and a writer, knowing that the words will take shape as I continue to immerse myself in the subject matter.

With this perspective, I'm ready to dive into the writing process wholeheartedly. I'm excited to let my thoughts flow, to explore the depth of my understanding of Hoarding Disorder, and to showcase the significance of this research. This is just the beginning of the journey, and I am eager to see the introduction evolve into a powerful and compelling piece.

So, here's to letting go of perfection and embracing the freedom to write without constraints. This journey is about growth, discovery, and the pursuit of knowledge. I will allow myself to write imperfectly because the act of writing itself is what will ultimately lead me to uncover the most profound and impactful insights.

With this newfound sense of permission, I'm ready to embrace the writing process with renewed enthusiasm. Let the ideas flow, let the words take shape, and let the thesis come to life. This is just the beginning, and I'm excited to see where this journey will take me. Onwards, with the courage to write fearlessly!

Journal Entry #15

Inspiration has found its way into my research journey, filling me with a renewed sense of motivation and determination. A colleague of mine recently completed their thesis and even applied for their CAP license, and witnessing their achievement has given me a much-needed push forward.

As I embark on this journey alongside my colleague, I've discovered some helpful resources that have become my guiding light. Watching informative YouTube videos about the process of completing a master's degree thesis has been incredibly valuable. These videos have provided me with valuable tips and strategies for creating a manageable timeline to finish my project successfully.

Armed with newfound knowledge and inspiration, I've set a clear goal for myself. My aim is to complete the literature review by the end of this month. This will give me ample time to send it to my supervisor for feedback and revisions. Having a specific target has made the task less daunting, and I'm feeling positively driven to achieve this milestone.

The excitement of reaching each milestone and inching closer to the finish line has become a fueling force. Witnessing my colleague's accomplishments and learning from others' experiences has given me the courage to forge ahead. The prospect of applying for my own CAP license after completing this thesis fills me with a mix of pride and anticipation. While challenges may still lie ahead, I feel equipped with the knowledge, support, and determination needed to face them head-on. I've come to realize that research journeys are not solitary endeavors but collective experiences, shaped by the wisdom and encouragement of those around us.

As I take each step forward, I embrace the process and the growth it brings. The lessons learned, the new insights gained, and the resilience developed along the way are all invaluable rewards of this journey. I'm excited to embrace the upcoming chapters, to see the thesis evolve, and to contribute to the growing body of knowledge in my field.

With the newfound inspiration and resources at my disposal, I'm ready to embrace the challenge of completing my thesis with enthusiasm and dedication. The end is in sight, and I'm grateful for the support that has propelled me forward. Onward we go, one step closer to achieving the goal of completing this research project with excellence and pride.

Journal Entry #16

Ecstasy fills me as I write this entry - I have finally finished the literature review for my research on Hoarding Disorder. The completion of this crucial section marks a significant milestone in my journey, and I cannot help but reflect on the hard work and dedication that went into shaping it.

Throughout the process, I was committed to ensuring that the themes and topics explored in the literature review truly focused on the different groups involved in my research. I wanted their stories and experiences to be at the forefront, allowing their voices to shine through the pages. By doing so, I aimed to highlight what we already know about Hoarding Disorder and identify areas where gaps in knowledge exist. I believe that the stories of people with HD, their families, children, and the general public offer invaluable insights into the complexities of this disorder. By centering their experiences in the literature review, I hope to shed light on

the impact of HD on various individuals and explore the factors that influence hoarding behavior from different perspectives.

As I look back on the extensive research and analysis, I feel a sense of pride and anticipation. I am proud of the comprehensive picture I have painted through the literature review and how it lays the foundation for the rest of my research. However, I also feel a twinge of nervousness about the feedback I will receive. Nonetheless, I believe that the hard work, diligence, and passion that went into crafting the literature review will shine through. I trust that my dedication to portraying the experiences and perspectives of each group accurately will be recognized and appreciated.

As I submit the literature review to my supervisor, I am filled with a mixture of excitement and anxiety. The feedback I receive will be essential in shaping the next steps of my research. I am open to constructive criticism and eager to refine and improve my work further. Overall, I am thrilled to have reached this point in my research journey. The completion of the literature review signifies progress and brings me one step closer to realizing my research goals. As I move forward, I am eager to delve deeper into the analysis, explore the narratives of individuals with HD and their families, and contribute to the growing understanding of this complex disorder. The path ahead may hold challenges, but I am ready to embrace them with determination and enthusiasm. Onwards, towards the next chapter!

Journal Entry #17

As I progress with my research, I've begun working on the methodology section of my thesis. It's a significant step in the process, but I find myself grappling with mixed emotions. While it's essential and necessary, I must admit that it's not my favorite part of this project so far, although I'm unsure why.

The methodology section is crucial in outlining the framework for the research and explaining the methods I will use to gather and analyze data. It provides the roadmap for how I will explore the world of Hoarding Disorder and gain insights into the experiences of those affected. Despite its importance, I find myself less enthusiastic about this section compared to other aspects of the research. Perhaps it's the technical nature of the methodology that feels a bit overwhelming. Ensuring that I accurately describe the research design, sampling methods, data collection, and analysis procedures can be challenging. I want to ensure that every detail is presented clearly and coherently, leaving no room for ambiguity.

Additionally, my current workload adds to the stress of managing the thesis. Balancing work, the practicum, and the research project can feel like a juggling act. While I'm working hard and dedicating myself to each aspect, the weight of responsibility and deadlines can be stressful. Despite the challenges, I know that persevering through the methodology section is essential. Once completed, it will provide the necessary structure for the rest of the research. I am committed to producing a comprehensive and methodologically sound thesis that contributes meaningfully to the field of Hoarding Disorder. To manage the stress, I'm making a conscious effort to practice self-care. Taking short breaks to clear my mind, engaging in mindfulness exercises, and spending quality time with loved ones helps me recharge and regain focus. The support of my supervisor and colleagues also serves as a valuable source of encouragement during these demanding times.

As I navigate this phase, I will remind myself of the bigger picture and the impact this research can have on individuals affected by Hoarding Disorder and their families. Every step, even the less enjoyable ones, contributes to the greater purpose of understanding and addressing this complex condition. With resilience and determination, I will forge ahead. I recognize that this journey may be challenging, but the rewards of contributing to the field of HD research make it all worthwhile. As I continue working on the methodology section, I am hopeful that clarity and a sense of accomplishment will emerge, moving me closer to completing a meaningful and impactful thesis.

Journal Entry #18

Relief washes over me as I write this entry - I have finally completed the methodology section of my thesis. It's been a laborious process, but I am pleased with the outcome. I have meticulously outlined the research design and data analysis procedures, ensuring clarity and precision throughout. However, amidst the sense of accomplishment, I find myself feeling stressed about something else entirely. It has been a while since I heard from my supervisor, and the silence is starting to worry me. I am anxious about whether something might be wrong or if I have missed an important update.

The lack of communication is unsettling, and I can't help but wonder if my work has fallen short of expectations. The thought of not receiving feedback or guidance from my supervisor makes me uneasy, especially as I near the completion of my thesis. I know that their insights are invaluable in refining and improving my research. As I progress through this phase, I am growing increasingly eager to finish the thesis. The more I immerse myself in my work, the more I yearn to move into the world of counseling. This research has been a significant

endeavor, and I am eager to utilize the knowledge and skills I have gained to make a meaningful impact in people's lives.

While I am grateful for the research journey and the insights it has provided, I can't help but feel a sense of restlessness to move forward with my career. The thesis feels like the final hurdle, and I am eager to cross it to open new doors of opportunity. Despite the stress and uncertainties, I remain committed to my research and the process of completing my thesis. I know that perseverance and dedication will see me through to the end. In the meantime, I must learn to manage the stress and uncertainty while maintaining focus and determination.

As I anxiously await communication from my supervisor, I remind myself that I am capable and have put forth my best effort. Regardless of the outcome, I am proud of the work I have accomplished so far. I will continue to channel my enthusiasm and passion for counseling into my research, knowing that this thesis is a stepping stone toward my goals. With hope and resilience, I push forward. I am eager to receive feedback, make any necessary revisions, and finally complete this important chapter in my life. As I look ahead, I envision a future where I can combine my research and counseling expertise to make a positive impact in the lives of others. Onward, towards the next chapter of this journey!

Journal Entry #19

Today marks a significant turning point in my research journey as I begin the process of data collection. It's an exhilarating yet nerve-wracking phase, where I find myself pondering where to begin and how my choices will impact the results.

As I delve into this phase, one of the initial questions that arises is whether to use the same sources of information for data collection or to gather data from different avenues. Each option comes with its own set of implications. Using different platforms and sources might offer a more diverse perspective on Hoarding Disorder and its impact on various individuals. On the other hand, using the same platform may allow for more direct comparisons and in-depth analysis.

The uncertainty of where to begin can be daunting. However, I remind myself that this research is an exploration into the world of Hoarding Disorder, and the results should not be forced to fit any preconceived notions or expectations. The aim is to discover, not to confirm pre-existing beliefs. The findings will be what they are, and that's the essence of the research process.

In my quest for answers, I also find myself asking questions about the volume of data to collect. How many posts and replies should I gather to ensure a comprehensive and representative sample? These questions remain unanswered for now, but I trust that as I immerse myself in the data sets, clarity will come.

As I embark on this data collection journey, I must embrace the unknown and allow the data to speak for itself. The richness of the information lies in its authenticity and unfiltered nature. The narratives of individuals with Hoarding Disorder, their families, and the general public hold invaluable insights that will contribute to a deeper understanding of this condition.

Navigating through this process with an open mind and a commitment to thoroughness will be essential. I will strive to be impartial and unbiased, allowing the data to shape the conclusions and implications of the research. The authenticity and diversity of the data will lend depth and credibility to the findings.

Though the road ahead may be challenging and uncertain, I am eager to embark on this phase of data collection. As I immerse myself in the narratives, posts, and replies, I know that the stories and experiences shared by participants will enrich the research in profound ways.

As I take this leap, I trust in my skills as a researcher and my dedication to this project. Each step forward brings me closer to unraveling the complexities of Hoarding Disorder and making a meaningful contribution to the field. I embrace the uncertainties and welcome the insights that will emerge from the data. I am ready to embark on this research adventure with courage, curiosity, and an unwavering commitment to truth and discovery. Onwards, into the world of data collection!

Journal Entry #20

I began my data collection with the Children of Hoarders Inc., public Facebook group. Originally, I had identified a Yahoo support group for the purposes of this assignment however, upon further investigation, it was noticed that this group was no longer available on Yahoo. Therefore, Facebook was consulted as an alternative. As it is a public group, there was no need to ask for entry to this group.

In selecting the data, I started by looking at the frequency of posts that the group made – noticing that they post rather frequently – almost daily. It was also noticed that posts did not seem to be initiated by group members, but rather by the administration team. This is also due to the settings of the group, whereby one cannot initiate a new discussion thread, but can only respond to the posts made by the administrators of the group. Though I could not find a rationale for this, the below screenshot represents the details of the group, as per their Facebook description:
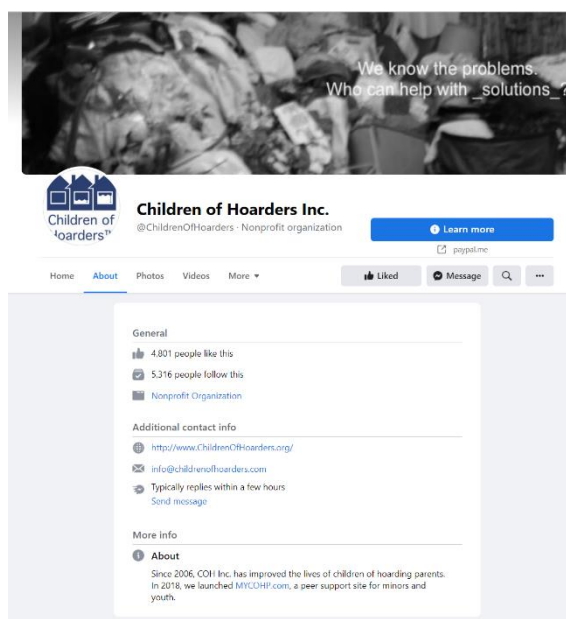
As there is a high frequency of posts, it was not difficult to find posts within the past year, as specified in my criteria for post-inclusion.

To select posts for analysis, I simply began scrolling down the page. I did not look at the screen and randomly stopped, at different time intervals, in order to generate a random polling of posts.
As not all posts had a significant number of comments (for example 2 or less), it was decided that 10 posts, and their comments, would be pulled for the initial analysis. This was decided in attempts to ensure that enough raw data was gathered in order to generate enough of a rich description of comments from the members, and topics of interest, as generated by the administrators.

Once a post was selected, I created 3 separate documents to help me track and inventory the data.

1. A record of the date and time of the post, the initiator of the post, the post's summary and the codes (which were later added during the thematic analysis).
2. A more detailed catalogue was created, which included the date/time of the posts, statistics surrounding the number of comments, shares and emoji reactions, if media was associated with the post and of what nature, and links or additional artefacts included.
3. An inventory which included the screenshots of the original post and all comments that were made in response.

I decided that these would be the starting point for the data collection, organization and basis for the thematic analysis. Though I haven't yet begun the thematic analysis, as I am still collecting all of my data, I do believe the third document is where I will perform the coding process. This may be more straightforward, at least to me, than NVivo. however, this decision may be changed at a later date.

Some observations about the posts and comments themselves were made during data collection:
1. Only the administrators could initiate a post
2. All posts selected had a photo included in the post. The photo varied in terms of its type and included: photos of actual hoarded spaces, and digitally 'drawn' images, which supplemented the ideas in the posts.
3. The hashtag: #ItsNOTJUSTClutter was always included and was always hyperlinked to either an accompanying article, blog, or website, which further elaborated on the topic of the initial post, or it was a link to the (presumed) source of the digitally 'drawn' media.

Journal entry #21

For the public's consideration of Hoarding, I decided to turn to YouTube as a source of information. This was decided because it is a very popular, free streaming platform, in which users often share recordings of television shows. I conducted a search by using the word 'hoarding' and found links to several different hoarding related shows. Rather than staying with only one show for data, I decided it would be a good idea to use a variety, in order to collect a range of threads and comments.

In selecting the videos to watch, the first area of interest was the date of the post. Again, I wanted to keep the data in the past two years, as these comments may be most current and contain the perspectives and insights surrounding hoarding disorder within the current pandemic landscape.

As with the previous data collection strategy, I generated the same three documents for the purposes of tracking and organizing the data:

1. A record of the date and time of the post, the initiator of the post, the post's summary and the codes (which were later added during the thematic analysis).

2. A more detailed catalogue was created, which included the date/time of the posts, statistics surrounding the number of comments, shares and emoji reactions, if media was associated with the post and of what nature, and links or additional artefacts included.

3. An inventory which included the screenshots of the original post and all comments that were made in response.

I felt that it would be prudent in maintaining consistency, which may also help with data analysis later on.

One main difference in this group, compared to the previous group, was the volume of comments associated with each post. For example, in the previous group, the maximum number of comments made in response to a post was 96, with a total of 148 comments distributed across the 10 posts. However, the number of comments were well over 100 for each video. Therefore, it would create an imbalance of data – providing a richer description of the public domain when compared to the COH FB group. Though generating a rich description is the aim of this project, analyzing such a number of comments is beyond the scope of data analysis for this project. Therefore, the decision to select the first 10 comments, and their first 10 replies, was made. This way, roughly the same number (approximately 100 posts and their respective comments) can be made across the groups.

Moreover, there are a few different Hoarding related programs in circulation. It was decided that, in order to gain a better perspective of comments from viewers, who may prefer one show over another, 2 videos from 5 different programs, will be used.

These shows include:

1. A & E's Hoarders

2. Only Human

3. Hoarding Buried Alive

4. Absolute Documentaries

5. (the British show with that guy who focuses on hoarding)

These shows most frequently occurred in the search using the keyword Hoarding/Hoarders, and are therefore deemed to be the most popular shows in circulation.

It is assumed that these different shows exist, not only because they are produced in different places, such as America and England, but because their formatting is slightly different and therefore viewers may gravitate to one over the other. That being said, there may be an overlap in viewers, who have no particular affinity for one show, but are simply interested in programs about Hoarding, in general.

Appendix C

Individuals with HD Thematic Codes and AQALs Classification

Meaning of Code	Code	Quadrant: I
Praise for Personal Progress	PfPP	
Why This Won't Work for Me	WTWWFM	
Self-Talk Used to Stay on Track	STUtSoT	
Suggestions to avoid being Overwhelmed in Clearing	StaOiC	
What do I/you Really Need?	WDIRN?	
Self-Talk About Keeping Items	STAKIs	
This is what works for me	TiWWfM	
Ideal Self stopping Progress	ISsP	
Fear of Missing Out	FOMO	
Guilt Mentioned	GM	
Self-Talk about Giving Items Away	STaGIA	
I'm Glad It's Gone	IGIG	
I'm Bothered Because of my Stuff	IBBomS	
I wish I could be like others	IWICBLOs	
I'm Overwhelmed	IO	
Personal Issues Stopping Progress	PISP	
I am getting help (i.e. therapy)	IGH	
Hoarding Issues since Childhood	HISC	
I want my life to be different/better	IWMYTBD	
Focus on the Positive	FoTP	
Starting/finishing is the hardest	S/FitH	
The Last Part is the Hardest	TLPitH	
If I could only bring X things with me, what would they be?	IFXWWTB?	
Struggling in Cleaned Areas	SiCAs	
Emotional distress from cleaned area	EDfCA	
Grief about losing hoard mentioned	GalHM	
Identity crisis as condition improves	ICaCIs	
I'm not used to the cleaned space	INUTCS	
I love Cleared Spaces	ILCSs	
Hoards make me feel safe	HMMFS	
The house is different after its cleared (sound/feel)	THID	
I prefer things to relationships	IPTs	
Hoards make me feel comforted	HMMFC	
My things bring me joy	MTBMJ	
Relationships make me Anxious	RMMA	
I prefer relationships to things	IPRTTs	
Hoarding Negatively Impacted my Relationships	HNIMRs	
In the Past, I preferred things to relationships	ITPIPTTRs	
Isolation mentioned	IM	
I'm Addicted to Despair	IATD	
Hoarding Is Attainable to Me	HIATM	

Meaning of Code	Code	Quadrant: It
Childhood issues related to hoarding	CIRtH	
I Hate People	IHP	
I can't be Normal	ICBN	
It's Lonely Not Having Relationships	ILNHRs	
I can relate to relationships with things	ICRTRWTs	
I don't want to leave a mess for others	IDWTLAMFOs	
I have more things than relationships	IHMTTRs	
I used to have a clear house	IUTHACH	
I hate myself because of my mess	IHMBMM	
Negative Emotions Mentioned	NEM	
I would have been upset by taking before pictures	IWUBPs	
I think I'm becoming a Hoarder	ITIBaH	
I look/act like a normal person but, my home is hoarded	IL/ALNPBH	
I will never hoard again	IWNHA	
Don't Avoid Your Emotions	DAYEs	
I love my Partner	IlmP	
Trauma Mentioned	TM	
I'm ready to change	I'MRTC	
I'm Worried the neighbors/landlord will find out	IWTN/LLWD	
I wish help was available	IWHWA	
Anxiety serves as a motivator for me	ASAMFM	
Emotional Attachment To Items Mentioned	EAtiM	
I deserve Better	IDB	
Meaning of Code	Code	Quadrant: It
Helpful Tool To Clear	HTTC	
Noticeable Progress Made	NPM	
I Hoard Clothes	IHC	
Suggestion to help with Keepsakes	SthwKs	
Description of Items in Hoard	DoInH	
Description of Items Left to Clear	DoILtC	
Recommended Resources to Help with Managing # of Items	RRM#Is	
Advice about items in Infested Hoards	AaiIHs	
Suggestions for Using Items with Others	SfUIwOs	
Recommendations for time limits on keeping items	RfTLs	
Recommendation to start from scratch (donate as much as you can)	RtSFS	
Don't Buy New Things	DBNTs	
I try to buy helpful things (i.e storage/cleaning)	ITtbHTs	
I don't finish what I start cleaning	IDFWISC	
Advice on dealing with Piles of Things	AoDwP	
I'm Trying to Improve my Organizing	ITtImO	
Recommended Resources For Self Help	RRfSH	
You have to Maintain your Cleanliness	YHTM	
Suggestions for Self-Healing to deal with Hoards	SfSHtdwH	
Trying new activities/social circles to help	TNA/SCs	
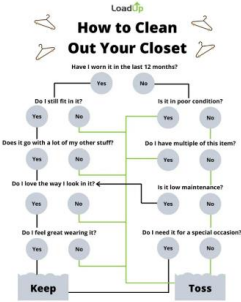
Meaning of Code	Code	Quadrant: We
Make your space work for you	MYSWFY	
Advice on keeping semi-hoarded areas	AoKSHAs	
How to get the echo out	HTGTEO	
Recommendations to Improve the Space	RtItS	
General Resources Recommendation (i.e., Youtube or Google)	GRRs	
Advice on how to differentiate between the visual or audio issue of the room	AOV/AI	
Hoarding Issues Since Teen Years	HISTYs	
Abuse linked with my hoarding	ALWMH	
I can't have people in my home	ICHPIMH	
I struggle to clear	ISTC	
Coping Mechanisms Mentioned	CMM	
Getting Things Helped Me deal with my relationships	GTHMDWRs	
Not Having a routine has led to my hoarding	NHARLTH	
I've finally started to clear	IFSTC	
I kept putting off my cleaning	IKPOMC	
Recommendation for tracking progress	RfTP	
I'm cleaning everyday	ICE	
I Hoard Paper	IHrdP	
Link to Resource	LtR	
COVID has impacted my situation	COVIDIS	
I need to go through everything for closure	INGTFC	
Beware of Needing To Go Through Everything	BoGTE	
If You Don't need it, throw it out	IYDNITIO	
Recommendations on dealing with paper-based items	RDWPBIs	
Recommendations for Seeking Help	RfSEEH	
Comorbid Condition Mentioned	CCMd	
Suggestions for Finding Therapy	SfFTy	
CBT Recommended	CBTR	
Set Personal Goals To Help	SPGs	
DBT Recommended	DBTR	
Recommendations to help with energy levels	RTHWELs	
Major Cleaning Push Today	MCPT	
Recommended Resources to Help with Managing # of Items	RRM#Is	It
Meaning of Code	**Code**	**Quadrant: We**
Asking for Clarification	AFC	
This is Useful	TiU	
Thank You	TY	
This is Not Useful	TiNU	
Generally Supportive Comment	GSC	
Advice about Monetary Value of Items	AaMVoIs	
Shared Experience	SE	
Agreed	A	
Does Anyone Else Have This Issue?	DAEHTI?	
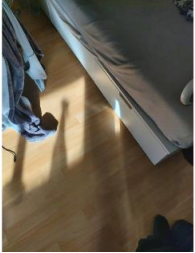
Meaning of Code	Code	Quadrant: Its
Asking for Advice	AFA	
I want to know I'm not Alone	IWtkINA	
You're Not Alone	YNA	
Hoarders Don't Like Cleared Spaces	HDLCSs	
Good relationships help my hoarding	GRHMH	
Relationships aren't available to me	RAATM	
Negative Relationships associated with Hoarding	NRAwH	
People Need To Be Heard	PNtbH	
Women Tend to Hoard More	WTtHM	
Hoarding is Taboo	HiT	
Negative Comment Removed by Moderator	NCRBM	
Clarifying Comment	CC	
Meaning of Code	**Code**	**Quadrant: Its**
Societal Issues affect Relationships	SIaRs	
My Roommate is still hoarding	MRisH	
My whole family hoards	MWFHs	
I had therapy but it didn't help	IHTBIDH	
Past Therapists Didn't Match My Needs	PTDMMNs	
I can't afford help	ICAH	

Appendix D

Individuals with HD Artefact Analysis

Artefact Name	Artefact image	Overall Frequency
Crying		4
confetti		1
Typed smile	:)	3
claps		3
smile		4
Flow Chart	**How to Clean Out Your Closet**	1
Crying/laughing		1

Picture of clear 1		1
Picture of clear 2		1
Picture of clear 3		1
Link		(Note: Emoji is my own choosing – this was never used by the participants)

		6

Children of Individuals with HD Thematic Codes and AQALs Classification

Meaning of Code	Code	AQALS Quadrant
Trigger Inducing	TI	I
Feelings Associated With Hoarding Disorder	FAWHD	
Don't Judge/Don't Judge Me	DJM	
Meaning of Code	**Code**	**AQALS Quadrant**
Hoarding Disorder and Narcissistic Personality Disorder	HD & NPD	It
Positive Attempts To Deal With Children of Hoarders' Experiences	PATDWCoHE	
Hoarding Disorder Behaviours	HDB	
Comorbid Conditions associated with HD	CCAWHD	
Healing/the Healing Process	HHP	
Ways to Prevent Hoarding Disorder/Hoarding Disorder Tendencies	WPHD	
Descriptions of Negative Relationships/Behaviours	DNRBs	
Meaning of Code	**Code**	**AQALS Quadrant**
Highly Negative Language Associated With Children of Hoarders' Experience (i.e., abusive/imprisoned/held-hostage)	HNLAWCoHE	We
Clarification of Terminology	COT	
Thank You	TY	
Agree/Agreement with Previous Post/Comment	A	
Shared Experience	SE	
General Supportive Comment	GSC	
Disagree/Disagreement with Previous Post/Comment	DA	
Admin Intervention to Smooth Things Out	AITSTO	
Clarification Of Post/Comment Content	COPCC	
Suggestions for Help/Resources	SFHR	
Descriptions of Healthy Relationships	DoHRs	

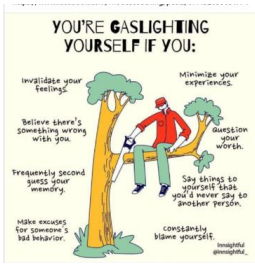| Reversal of Roles Children Caring for HD Parents	RoRCCHDP	
Dependency/Co-Dependency	DCD	
Positive Affirmations towards Personal Improvement (i.e., you can break the cycle)	PATPI	
Where do We Go From Here?	WDWGFH?	
Ambiguous Comment	AC	
Meaning of Code	**Code**	**AQALS Quadrant**
Psychologists Siding With Hoarders Not Children of Hoarders	PSWHNCoH	Its
Call For More Research	CFMR	
Link To Research	LTR	
Critic of Media Portrayals Of Hoarding Disorder	COMPOHD	
Critic of Understanding Of Hoarding Disorder and/or Comorbid Conditions	COUOHDCC	
Lack of Parental Responsibility	LOPR	
Classification Of Hoarding Disorder (i.e., reference to DSM-V or other Classifications)	COHD	
Clinical Terminology (i.e, anxiety, OCD, NPD etc)	CT	
Negative Effects of Parents' Behaviour	NEOPB	

Appendix F
Children of Individuals with HD Artefact Analysis

Artefact	Symbol	Frequency
Like		134
Hug		50
Love		130
Swearing emoji		1
Betty White GiF		1
Blue heart		4
Red heart		2
Heart in eyes emoji		1
Picture of home		1
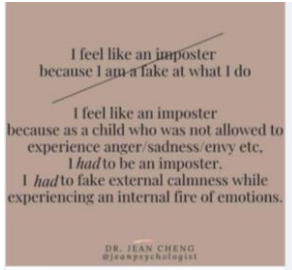
Shocked emoji	😮	7
Sad emoji	😢	76
Laughing emoji	😆	9
Angry emoji	😠	
Crying emoji	😢	65
Smile emoji	😊	1
Happy emoji	🙂	1
Eye rolling emoji	🙄	1
Dunno emoji	🤷‍♀️	1
Hand over mouth	🤭	1
Sad face emoji	🙁	1
Disappointed face emoji	😔	1
Hand clap emoji	👏	4

Picture 1		1
Picture of home 2		1
Picture 2		1
Picture 3		1
Picture 4		1
Picture 5		1

Picture in post 6	I feel like an imposter because I am a fake at what I do I feel like an imposter because as a child who was not allowed to experience anger/sadness/envy etc, I *had* to be an imposter. I *had* to fake external calmness while experiencing an internal fire of emotions. DR. JEAN CHENG @jeanpsychologist	1
Picture in post 7	**If you come from a dysfunctional family, you may have promised yourself something like...** • "I will not end up like my mom." • "My kids will not feel the way I did growing up." • "I will never be with someone like my dad." • "My marriage will be nothing like my parents'." • "I'll never turn into the kind of parent I had." • "When I get out, my house will feel like a home." @miranda.m.wise	1
Hashtag 1	#ItsNotJUSTClutter	
Link 1	https://www.facebook.com/ChildrenOfHoarders/posts/10156929974170831	1
Link 2	https://youmemindbody.com/mental.../Are-Hoarders-Narcissists	
Link 3	https://www.lovewhatmatters.com/woman-shares-journey.../	1
Link 4	https://www.facebook.com/rhodescoaching/posts/677152053631774	1
Link 5	https://www.psychologytoday.com/.../how-undo-the-damage...?	1
Link 6	https://www.facebook.com/.../a.12345194.../4407644975950174/	1
Link 7	https://www.facebook.com/.../a.28615697.../4911235538901064/	1

Appendix G
Friends and Family Members of Individuals with HD Thematic Codes and AQALs
Classification

Meaning of Code	Acronym	AQALS Quadrant
Feeling Overwhelmed	FO	I
Trauma is Mentioned	TM	
Hoarder's Perspective – Hoarding Holds Me Back	HPHHMB	
Hoarder's Perspective – How I am Learning To Understand and Cope	HPHILTUAC	
Lack of Understanding of Family Member's Behaviour	LUFMB	
Want to Help but Can't	WHBC	
Guilt Mentioned	GM	
Fear Mentioned	FM	
Fear of Contamination	FoC	
I Hate Living This Way	IHLTW	
You Need To Do What's Best For You	YNTDWBFY	
Pressure from Others For Intervention (i.e., other family members)	PFOFI	
Concerns about Health	CAH	
Shame Mentioned	SM	
Would This Really Be Helpful?	WTRBH?	
Feeling Confused/Unsure What to Do	FCUWTD	
Things Are Getting Worse	TAGW	
Must Put The Kids First	MPTKF	
Doubtful Things Will Be Different This Time	DTWBDTT	
Childhood Experiences Influence Hoarding	CEIH	
At the End of my Rope	EOMR	
Description of 'What I Wish it Were Like"	DWIWIWL	
Possible Consequences of Current Situation (i.e., infestation or sickness)	PCCS	
Don't Go Too Much Out Of Your Way	DGTMOOYW	

Meaning of Code	Acronym	AQALS Quadrant
Description of Family Member's Behaviour	DoFMB	IT
Family Relationships are Suffering due to Family Member's Hoarding	FRaSFMH	
Past Interventions Unsuccessful	PIU	
Recommending Self Help	RSH	
Recommending Improving Safety of Family Member's Home	RISoFMH	
Recommendations to Include Family Members in Household Changes	RIFMHC	
Recommending Resources	RR	
Possible Explanations of Family Members Hoarding Behaviour	PEoFMHB	
Focus on Improving Living Conditions for Safety	FILCfS	
Focus on Improving Living Conditions for Daily Activities (i.e. showering/cooking)	FILCfDA	
Recommendations on how to Approach Cleaning a Hoard	RACH	
Recommendation to Not Intervene	RNI	
Forced Cleanouts Don't Work	FCDW	
Hoarder's Perspective- I'm Making Progress	HPIMP	
Comorbid Health/Mental Health Conditions Mentioned	CHMHM	
Recommendation to Lead By Example (i.e., you clean up your stuff)	RLBE	
Family Members Mentioning Progress	FMMP	
Addiction Mentioned	AM	
Self Harm Mentioned	SHM	
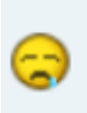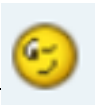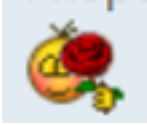
Meaning of Code	Acronym	AQALS Quadrant
Action Plan Mentioned	APM	
Setting Boundaries	SB	
Relapse	R	
Family Member's Coping Strategies	FMCS	
Focus on Hoarder Not Family	FHNF	
Deception Used To Help Hoarder	DUTHH	
Recommendations to Protect Animals Involved	RPAI	
Recommendation to get Other Family Members Involved	ROFMI	
Meaning of Code	**Acronym**	**AQALS Quadrant**
Asking For Advice	AFA	We
Reply Asks for Clarification	RAFC	
Recommendations to ask Family Member About How To Help Them	RtaFMAHTHT	
Agree with Previous Post	A	
Comment Shows Sensitivity	CSS	
Reassurance the you're doing your best given the situation	RYDYBGS	
Hoarders Need Support and Presence	HNSP	
Shared Experience	SE	
Hoarding is Complicated /Difficult to Understand	HCDTU	
Administration or Technical Problem	ATP	
General Supportive Comment	GSC	
Thank You	TY	
Acknowledging The Efforts of Others (sharing experiences etc.)	ATEO	
Love (in salutation or positive wishes to others)	L	
Hoarders Need Love	HNL	
Recommendations on how to Talk to Family Member	RHTFM	
Suggestion Not Helpful/Applicable	SNHA	

Recommendation To Access Medical/Social Services	RAMSS	
Insensitive Response	IR	
Meaning of Code	**Acronym**	**AQALS Quadrant**
Family Member Doesn't Recognize Their Problem	FMDRTP	Its
Family Member Can't Care For Themselves	FMCCFT	
Family Member's House Isn't Safe	FMHIS	
It's the Family Member's Responsibility, Not Yours	IFMRNY	
Unhelpful Medical Services	UMS	
Attempting to Access Social Services	AASS	
COVID Complicating Relationships with Hoarders	CCRH	
Family Member's House Isn't Working Properly (i.e., no hot water)	FMHIW	
Finances are Suffering Because of Hoarding	FSBH	
Therapists Don't Understand What It's Really Like to Be a Hoarder	TDUWHDI	
Hoarders Finances are Suffering	HFS	

Appendix H

Friends and Family Members of Individuals with HD Artefact Analysis

Artefact name	Artefact Image	Total
Happy face with flower		2
Smiley Face		2
Typed Heart	<3	1
Dunno emoji		1
Frustrated Face		2
Frowny /crying face		1
Winky face		1
Crossed-eyed face		1
Crying and tear		1
Typed smile	:)	1
Blushing happy face with flower		1
Typed frown	:(	1
Link to resource	Direct link to website or other resource	10 (Note: this was never used by the participants)

Appendix I

General Public Thematic Codes and AQALs Classification

Meaning of Code	Acryonym	AQALS Quadrant
Negative Language Used (about hoard/conditions)	NLU	I
Unfair Treatment Towards Hoarder (in show)	UTTH	
Commentor Mentions Their Ongoing Struggles	CMtOS	
Wanting To Clear House To Make It Easier On Others in the Future	WCHEooF	
"Helping" isn't always Helpful	"H"IAH	
Advice About What Hoarder 'Should Do"	AAWH'SD'	
Self-Talk Associated with Progress	S-TAWP	
Positive Comment about Therapist in show	PCaT	
Negative Comment about Therapist in show	NCaT	
Positive Comment about Helpers in show	PCaHs	
Negative Comment about Helpers in show	NCaHs	
Knowledge about HD gained from watching Previous Episodes	KaHDWPE	
Best Episode Ever	BEE	
Pity People in the Show	PPitS	
Speculation about Show Content (i.e., people's actions/thoughts/feelings)	SaSC	
Second Chance is Needed	SCiN	
General Opinion	GO	
Comment Views Hoarding as an Illness	CVHaaI	
Comment Separates Hoarder from Illness	CSHfI	
Wish More People Would Try and Understand Hoarding Better	WPTUH	

Meaning of Code	Acryonym	AQALS Quadrant
Surprised about Comments/Reactions	SaC/Rs	
I'm Worried About Becoming a Hoarder	IWaBaH	
Comment Regarding Cleaning A Hoard	CRCaH	
Positive Comment about the Show Compared to other HD Shows	PCatS	
Comment Views Hoarders as Addicts	CVHaAs	
Shame Mentioned	SM	
Description of Negative Emotions with Hoarding	DoNEwH	
Watching these shows helps me with my personal life (not hoarding but other areas)	WttHM	
I need to get organized	INTGO	
Negative Opinion about the Show – doesn't help the people & doesn't benefit society	NOatS	
Negative Judgement about the Presenter/Host	NJaP	
Pity the Neighbors	PiT	
Positive Comment about the Show	PCatS	
Trauma Mentioned	TM	
Meaning of Code	**Acryonym**	**AQALS Quadrant**
Description of Hoard	DoH	It
Commenter Mentions they Hoard/somewhat Hoard	CMtH	
Watching Shows Helps My Hoarding	WSHMH	
Hoarders Gain Insight Through Watching	HGItW	
Hoarder Commenter Mentions They've Made Progress	HCMTMP	
Commentor Mentions their Progress	CMtP	
Keep Useful Things	KUTs	
Strategies for Making Progress	SfMP	

Meaning of Code	Acryonym	AQALS Quadrant
Speculation about Hoarding Behaviours	SaHBs	
Description of Hoarding Behaviours	DoHBs	
Concerns for Safety	CfS	
Concerns about Health	CAH	
Comment Mentions Comorbid Conditions (i.e., OCD, Anxiety)	CMCCs	
Watching these shows helps me get rid of things in my house (not a hoarder)	WtsHMGR	
I like getting rid of my extra stuff	ILGR	
Strategies for Staying Organized	SfSO	
Meaning of Code	**Acryonym**	**AQALS Quadrant**
Positive Comment About Hoarder	PCAH	We
Agree	A	
Negative Judgment about Hoarder	NJaH	
Negative Judgment about Hoarding Behaviours	NJaHB	
Disagree	DA	
Positive Comments about Children of Hoarder	PCaCoH	
Positive Comments About Family of Hoarder	PCaFH	
Negative Comments about Family Member of Hoarder	NCaFMoH	
Positive Comment about Friends of Hoarder	PCAFsoH	
Direct Quote from Post Repeated	DQfPR	
Supportive Comment For Hoarder (in show)	SCfH	
Shared Experience	SE	
Commentor Mentions they are like Another Commenter	CMtaraC	
Generally Supportive Comment	GSC	
Positive Comment About Hoarder's House	PCaHH	
Defensive Comment	DC	

Defensive Reply	DR	
Commentor Feels Connected to Hoarder	CFCtH	
Commenter is a Family Member of a Hoarder	CiFMoH	
Commentor Sharing Personal Feelings About Episode	CSPFaE	
Negative Attitude Towards Hoarding	NATH	
Isn't This Abuse?	ITA?	
This Show Can Help People With Hoarding	SCHP	
This Show Can Educate People About Hoarding	SCEP	
Everyone In This Situation Has A Responsibility Not Only The Hoarder	EitsHR	
Sad Update About Show Members	SUaSMs	
Commentor is Associated with Cast Members	CiAwCMs	
Asking for Clarification	AfC	
Clarification Given	CG	
We need to care more for our neighbors	WNTC	

Appendix J

General Public Artefact Analysis

Artefact Name	Artefact	Frequency
Red heart		2, 1,2, 2, 1,1,1
Sad eyes		1, 1
Heart smile		11111
Thumbs up		2,1, 1
Starry eyes		1
Star emoji (twinkle version)		1
Pink Heart		1
Smiley face		1, 1, 1, 1, 1
Smiley & Hug face		7,2, 1, 1
Crying face		1, 1, 1, 1, 3,1,1,
Face palm		1
Distressed face		1
Sad face		1,1

Hands up		1, 3
Sideways laughing		1, 1, 1, 3
Red angry face		1
Brain Exploding		1
Big eyed/blushing		1
Red Angry Emoji		1
Eye Rolling Emoji		2, 1, 1, 1, 1
Prayer Hands		1, 1, 1, 1
Purple Heart		3, 1
Fist up		1
Pink Sparkle Heart		1,1
Laughing emoji		1,1
Monkey Covering Eyes		1 (no comment with this)
Squinting laughing		1

Heart Eyes emoji	😍	1, 1
Okay hand	👌	1
wink	😉	11
Nice house	🏠	1,
Brick wall	🧱	1,
Old house	🏚	1
Squinty face	☺	1, 1
Nice house 2	🏠	1
Worried with sweat	😓	1, 1
Heavily crying face	😭	1, 1, 1, 9 4,
Frown face	☹	1,1,1
Looking down	😔	2
Typed-frowny	:(	1
Peace sign	✌	1
Thinking emoji	🤔	1, 1

lying	😔	1
Typed heart	<3	1
Wearing glasses	🤓	1
Grinning	😁	4
2 small pink hearts	💕	1
Hashtag #sorry	#sorry	1
Timestamp	timestamp	1
X (Kiss)	X	1

Appendix K

Athabasca University
RESEARCH CENTRE

CERTIFICATION OF ETHICAL APPROVAL - RENEWAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **24628**

Principal Investigator:
Ms. Tracy Quayat, Graduate Student
Faculty of Health Disciplines\Master of Counselling

Supervisor/Project Team:
Dr. Murray Anderson (Co-Supervisor)
Dr. Paul Jerry (Co-Supervisor)

Project Title:
Digital Ethnography and Hoarding Disorder: The Insider's Perspective

Effective Date: February 21, 2023   **Expiry Date**: February 20, 2024

Restrictions:

Any modification/amendment to the approved research must be submitted to the AUREB for approval prior to proceeding.

Any adverse event or incidental findings must be reported to the AUREB as soon as possible, for review.

Ethical approval is valid *for a period of one year.* An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

An Ethics Final Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: February 02, 2023**

Barbara Wilson-Keates, Vice-Chair
Athabasca University Research Ethics Board

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