Contemporary Science-Medical Writing; O'Connell

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Word Count: 1478 11/24/2024

Name of a potential publication/market: Mental health-centered publication... this piece will be published on my blog about hoarding, which can be found at buriedbutbreathing.com

Designated audience: those inflicted by a hoarder in their lives and the general public

Form: Feature story with testimonials from other adult children of hoarders and slight touches of personal essay

## Improving the Narrative Around Hoarding

Seeing piles of biohazardous human waste and trash, decomposing skeletons of dead domesticated animals who starved to death amidst the chaos, and looming mountains of random possessions while clicking through a streaming service must be jarring for most people of the general public. Hoarding-focused TV shows, like A&E's *Hoarders*, TLC's *Hoarding: Buried Alive*, and Netflix's *Tidying Up with Marie Kondo*, have gained traction on popular streaming services for their depiction of the hoarder lifestyle. According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, only about 2.6% of the population of the United States reports having a hoarding disorder, so for the general majority, it must be hard to stare at the screen and imagine having to live in that situation. But for adult children of hoarders like myself, it's not hypothetical. We either lived in it for most of our childhood and lives, currently live in it, clean up after it, or are haunted by it daily.

According to some adult children of hoarders, the problem is that these television shows, which are the primary entertainment industry and source of accessible public information about hoarding, often give the wrong perception and provide the general public with misconceptions about the mental health disorder. Hoarding disorder, which became a diagnostic entry in the *DSM-5* in 2013, is a diagnosable mental health condition, a fact that seems mostly unknown.

"[They're] exploitative of the people, and it's voyeuristic, but at the same time, I feel like I have such a connection to it that I can't help but see it as more real, not just something to make fun of," says 32-year-old Emma. For as long as Emma can remember, her father has been an avid hoarder. She recalls her earliest memories of her father's hoarding, which happened when she was six and her brother was three. Since then, her father has accumulated incessantly, filling his space to the point where the only place Emma can sit when she visits her mother is a single uncomfortable wooden chair at the kitchen table.

57-year-old TN's experience differs from Emma's in that her mother started hoarding when she had already left the house for college. The first time she noticed the hoarding was in 2001, when her mother's home flooded for the second time during Tropical Storm Allison, the first being in 1979 with Tropical Storm Claudia. Although the house only had about a foot of water at that time, TN, her husband, and her teenage son became aware that her mother had put old newspapers, phone books, wrapping paper, and unusable clothing into two storage units to prevent them from getting soiled by the flood. This was just the start of the hoarding. Years later, when her father died in 2008, TN discovered that the garage, which had also flooded in 2001, had not been mucked out after the second major storm.

"It looked like it had been through a muddy washing machine. There were dead animals in the contents and insects, and just a layer of dirty silt all over everything after the water had

drained out of the garage," recollected TN as she described her revelation of her mother's mental health disorder. Like Emma, TN struggles to watch television programs that involve hoarding and agrees that they misconstrue the truth and approach the problem incorrectly.

"If you watch the *Hoarders* TV show, allowing people to touch everything and make decisions and coddling them is the wrong approach. I think the only time the mental health professions should get involved in it is when the hoarder seeks help themselves because otherwise, it's an incurable, progressive, sometimes fatal disease."

For 41-year-old Penelope\*, who has been forced to resume living in hoarding conditions because of issues with flooding in her home, the trouble is that some people in her life have a hard time understanding what it means to be a hoarder because of the misinformation displayed throughout hoarder TV shows. On top of that, Penelope thinks that hoarding is both a culturally-accepted addiction and mental illness.

"I know people my age, like this one couple I'm friends with, where the wife is a hoarder. That's the one thing they fight about in their marriage. The husband does not accept that his wife is a hoarder because it doesn't look like the TV shows," says Penelope.

For Emma, one of the common misconceptions that she has heard is that hoarding is not a mental illness. For TN, the widespread myth, often spread by hoarding television series, is that cleaning it up will fix the problem and that the children have any control over what their parents do. TN also realizes that there's a lot more anger and verbal abuse on the part of the hoarder to their families than people ever understand. For Penelope, the assumption that hoarders always live alone is false.

"There's a lot of blame on family members. Hoarders will resort to violence to protect their items, and the general public does not understand that. I hear a lot, "But it's your parents,"

but I don't believe that people should have to associate with their abusers. And hoarding is abuse," says TN.

Alongside the inaccuracies and falsifications produced by one of the biggest public industries for hoarder communication, the societal stigma and shame surrounding the treatment of and discourse about hoarding have made dealing with a hoarder family member a grueling and lonely task for some adult children of hoarders.

"I'm glad to have a brother or a sibling because I feel less alone. Sometimes, we can laugh about it or find some humor now that we're older. If not, it would feel much more lonely," says Emma. For most of her life, Emma thought that her father's condition was an isolated issue, not realizing until much later that it is part of a more significant phenomenon shared by a multitude of individuals.

For Emma, TN, Penelope, and myself, the sense of loneliness and search for answers came to a turning point with the discovery of children and family members of hoarders support groups on Facebook. Emma and Penelope found a community in 2023, TN, in 2017, and I found two in 2020, when I was 19.

Emma decided to find a community for children of hoarders after she and her father had an enormous fight about the hoarding. TN joined one of the Facebook support groups after Hurricane Harvey, another tropical storm that shook her mother's hoarded home for the third time, forcing TN to clean out, reconstruct, and sell the house to protect her mother and her own health and sanity. Penelope entered a page after she was obligated to return to her mother and stepfather's abode when her previous permanent residence flooded and filled with mold, waiting for her new home to be renovated.

For Penelope, living in the hoard makes her feel "borderline suicidal" because she feels like there is no end, but she finds comfort in the ability to interact with others like her online. These private online communities, where individuals connect through shared experiences and pictures, seek advice, and find emotional support in one another, have made a real difference in Emma's, TN's, and Penelope's lives.

"I feel like it was very helpful because I got to read everyone else's stories and see that it wasn't just something I was dealing with," says Emma.

"I [find] it amazing. It's amazing support, knowing that there are so many people out there who have the same struggles, and the lack of judgment of that group is amazing," says TN.

"I'm really glad for that Facebook support group because it lets me know that there are other people out there dealing with the same bullshit I have to deal with," says Penelope.

In a world where media portrayals of mental health often fall short and in-person resources for families of hoarders are rare, online support groups like "Adult Children of Hoarders," with its ten thousand plus members, and "Family and Friends of Hoarders Support Group," with its seven thousand plus members, represent a powerful tool in the fight against misconceptions and for better treatment options for hoarders and their families. In this corner of Facebook, family members of hoarders have created a space for understanding and healing, focusing on building awareness, finding practical solutions, and improving the narrative around hoarding.

While hoarding still remains a stigmatized and misunderstood issue, the people who are helping keep these communities alive are shifting the conversation from one of shame and ostracization to one of empathy, education, and support, even for hoarders themselves, who occasionally write a message on the page looking for advice and offering perspective. For me, a

young woman still wrestling with acceptance and complete comprehension of my mother's mental health disorder, these groups provide a reminder that I am not alone in my struggles.

\* This source was given a pseudonym to protect their anonymity because of issues with housing insecurity and the danger of being homeless if exposed.

## References

- American Psychiatric Association, 2022. Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision. American Psychiatric Association Publishing, Arlington, VA.
- Interview with Emma
- Interview with TN
- Interview with Penelope