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Children in hoarded homes: A call for protection, prevention, intervention and compassionate care

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Practice Commentary

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Abstract

This is a call for action to protect and assist children of hoarding parents. Action that minimises harm to children living in hoarded homes also promotes family safety and health. Optimal care involves the whole family system, both children and parents. Prevention of harm through early identification and intervention for hoarding can reduce the burden of a disorder that often increases in severity over a lifetime and deprives humans of a full and safe life. Helping children and their parents severely affected by hoarding disorder is for the public good. Public policy and funded programmes can reduce long-term and immense costs to children, families and the many systems hoarding affects. Specifically, public policy can facilitate and fund outreach, education, coordination of providers of health, social and public services, and research-driven methods for assessment and intervention on behalf of children, individuals and families. Releasing people from the grips of hoarding disorder can enable them to devote generative resources to themselves, their families and their communities. Ultimately, prevention of hoarding through early assessment and intervention for minors and young adults is the most efficient, long-term and cost-effective method for minimising harm. When unidentified, hoarding disorder intensifies, people go into hiding, risk increases and opportunity for detection and intervention decreases. Informing the public about hoarding disorder must be followed with sufficient resources to address it, otherwise, helplessness ensues, and people will likely remain in the hidden world it governs.

Introduction

Helping children and their parents severely affected by hoarding disorder is for the public good. Prevention of hoarding through early assessment and intervention for minors and young adults may be the most efficient, long-term and cost-effective method for minimising harm. When unidentified, hoarding disorder intensifies, people go into hiding, risks increase and opportunity for detection and intervention decreases. Public policy can facilitate and fund outreach, education, coordination of providers of health, social and public services, and research-driven methods for assessment and intervention on behalf of children, individuals and families. Resources must be available when an informed public asks for help.

World and domestic organisations have policies that direct resources to identifiable threats to human health. International recognition of child safety, protection and rights was celebrated in 2019 at the 30th anniversary of the United Nations Convention on the Rights of the Child. Organisations, such as United Nations International Children's Emergency Fund (now United Nations Children's Fund), focus on relieving children who are suffering from the most abhorrent neglect, hazardous conditions, health threats, inadequate resources, victimisation and abuse. Videos and photos are shown of starving children in the arms of bewildered mothers, children held in brutal captivity and children who are victims of disease and war.

Among images of children in distress, we rarely see photos of them in badly hoarded homes, as seen in the TV show Hoarders (Butts et al., 2009) or described by adult children raised in such homes. In pleas for aiding children in harm's way, we do not see a teenager sleeping on a soiled mattress atop heaps of insect-infested garbage, a girl who hides clean clothes washed at grandmother's house in plastic bags so that her clothes do not stink at school or a boy who only had cold-water showers with animal waste collecting between his toes. Pictures are not seen of good food intermixed with bad, whole families sleeping on a couch or small floor space, and children with no place to study, play and share activities with the family. We do not see children cautiously navigating tunnels of objects while walking on floors surfaced with waste from faulty plumbing, rubbish, rotting food, debris and sharp objects. We do not see children in homes void of usable appliances, hot water or electricity. Children in badly hoarded homes can get respiratory ailments and skin conditions from infestations, poor hygiene and exposure to waste.

Children's fears abound in hoarded homes. They fear hazards that threaten their safety, such as mould from water damage, flammable objects on stoves, collapsing piles of objects and

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blocked doors, windows and passageways that prevent rapid escape from fire. Fear of physical endangerment is common.

Beyond fears of physical conditions, there is fear of discovery, the unexpected visitor at the front door ('doorbell dread'). Fears, shame, embarrassment and parental control deprive children of socialisation. Fear of social discovery and parental disapproval lead to never having friends inside the house. An odour typical of life in a hoarded house motivates them to cleanse in the school gym or free public facilities. Some are 'homeschooled' because parents fear attention from authorities. Children work to maintain the family secret, fearing parental anger, rejection and blame if they violate the code of silence. They see their parents' need to control the world of objects as a primary family focus, so these children often feel worthless, afraid and helpless.

We must rally many resources to address a widespread but unseen disorder that harms children and their families, a disorder that exists in many neighbourhoods, in both poor and wealthy homes. Hoarding disorder (The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013)) is a mental health/health crisis entrapping families and children throughout the world. We can no longer turn a blind eye to a disorder possessed by 2–5% of the population (Iervolino et al., 2009; Mueller et al., 2009; Postlethwaite et al., 2019; Samuels et al., 2008), a disorder that culminates in human suffering, hardships, health and safety hazards and, in some cases, death from hazards. Dr. Stuart Whomsley, who has engaged in direct treatment and advocacy for people at risk in severely hoarded homes, with others, wrote about good practice guidelines for hoarding disorder (Holmes et al., 2013). He and many others are drawing attention to helping people with this potentially life-threatening disorder.

Experiences of children raised in Hoarded homes

In 2011, I conducted an online survey of adult children raised in hoarded homes. Although many of the 678 initial participants gradually discontinued responding to queries, over 400 of them answered questions highly relevant to this commentary. The major flaws of the survey were its length and time necessary to complete it. Respondents answered questions about personal experiences across their lifespans. This provided their view of the progression of hoarding and how they were affected through stages of their development, from early childhood to adult life. I also gathered information from 30 mailed and completed surveys, 10 structured telephone interviews, the two summits for adult children held in New Orleans, emails and several unstructured telephone conversations. A few reports came from my clinical sessions with adult children of hoarding parents.

Regarding their years in the home, many respondents to the survey reported the following challenges. Family dynamics became increasingly dominated by hoarding. Family rules for the flow and placement of objects obscured usual family needs and opportunities for healthy family interaction. Intimacy and parental guidance were limited. Cultural norms of family life and traditions were squeezed out by objects. The boundary between the family's private and public worlds thickened as the home became more hoarded. Some families lost full participation in a community and social relationships were restricted or damaged.

The family homes lacked positive family routines and traditions. As youths, they developed ways to hide the truth from friends and borrowed common social references to a normal life. Many feared discovery and feelings of shame and embarrassment increased social isolation, while others sought more socialisation and activities to escape the home and fulfil needs and desires. Many did not accept social invitations realising that they could not reciprocate the offer, while others accepted offers so that they could use opportunities to eat, bathe, wash clothing and celebrate holidays.

Regardless, basic activities (studying, doing homework, eating, bathing, washing clothes, etc.) were challenging. Hoarding parents created strong limits on children's independent choices regarding space and stuff. Actions accommodated the hoard and the needs of the hoarding individual. These children had a diffuse and limited sense of ownership and feared parental responses to perceived threats to the hoard or hoarding behaviour, responses that were often inconsistent and unpredictable.

These children experienced emotional pain but did not expose the truth beyond the confines of the hoarded house. Words they use to describe childhood are suffocated, afraid, dirty, bad, alone, anxious, ugly, disgusted, ashamed, unloved, neglected, overwhelmed, crowded, embarrassed, guilty, angry, sad, lonely, confused, disconnected, depressed, hopeless and suicidal. Depression and anxiety were common in many periods of life, but adolescence seemed particularly strong for anxiety and depression, a time when many suffered from low self-worth, embarrassment and shame.

Like all children, they wanted parental acceptance, validation and nurturance and a family life that was healthy and fulfilling. They hoped that the non-hoarding parent could have made things better. Forced separation from family members and fear of unknowns about living with strangers were frightening. Their home, even if harmful, would be a familiar environment and one for which they acquired coping mechanisms. Many just wished that someone would have helped them and waited for an opportunity to have an independent life.

Some children of hoarding families entered the world beyond the home and sought refuge in schools, libraries, gyms, extracurricular activities and homes of neighbours and relatives. Children who secured access to the world beyond the hoarded home learned to navigate divided worlds, the hoarded home and the world beyond it. Regardless, the home's interior was shielded from others, and children internalised shame, fear and dread associated with discovery (Tolin et al., 2008). Extended family members often do not intervene to help the children.

Children of hoarding parents either eventually walked away or never left. Many faced the burden of trying to protect a disabled or aged family member from a hazardous life. As adults, they could not allow their children to visit grandparents in the hoarded home so there was a loss of family sharing and tradition. Ultimately, the inheritance was a hoarded or condemned family home and, more importantly, a loss of healthy family history. Most respondents to the survey said that their deceased parents hoarded as long as they could. Family fracturing was common. Greater than 80% of adult children of hoarding parents felt overly distant from parents, even the non-hoarding parent, and more than 70% felt overly distant from siblings.

The results from this survey were consistent with earlier research (Tolin et al., 2008) on the effects of parental hoarding. Tolin and colleagues (2008) concluded that children who grew up with hoarding parents had a less happy childhood, more difficulty making friends, fewer people over to the house, more arguments and a more strained relationship with parents, and more embarrassment about the conditions of their home. Later, Neziroglu and Donnelly (2013), after collecting data from adult

children of hoarding parents, addressed how to handle issues with their parents and resolve resulting personal concerns. The hope was that the families could build more peaceful and healing relationships and parents would accept help for their disorders. Even if this did not occur, adult children were encouraged to find peace, worth and health. Children of Hoarders, Inc., launched in 2006, is a non-profit organisation that provides understanding and support for adult children of hoarding parents, and Minor and Youth Children of Hoarding Parents, launched in 2018, provides minors and youths of hoarding parents with support, information and a way for them to share experiences.

Parents in severely hoarded homes live in a world of contradictions and paradoxes. Harmful conditions and processes are often unrecognised, left unattended and are shielded from intervention. Recognition of abusive conditions in hoarded homes is often compromised by co-morbidity, low motivation, cognitive challenges, fear of change and loss and a strong attachment to a process that feels rewarding (Grisham et al., 2010). They tend to have limited insight (Tolin, Fitch et al., 2010) into symptom severity and how their symptoms harm themselves and others. Paradoxically, the discovery of home conditions increases their fear and shame: 'There isn't anything wrong, but I must hide'.

This persistent and omnipresent disorder becomes a guarded family secret. Manipulation of family behaviour to maintain the secret and allow an unrestrained hoarding process is at the core of family dysfunction and control. Symptoms envelop and shape family dynamics (Park et al., 2014) and override the children's need for safety. Hoarding parents fear discovery because it threatens freedom to self-manage relationships with objects and to protect what these relationships are felt to supply, such as comfort, satisfaction and relief from deep emotions associated with unspoken traumatic experiences, and psychological ownership (Chu et al., 2018; Cromer et al., 2007; Hartl et al., 2005; Tolin, Meunier et al., 2010). Trust building is the foundation of any successful intervention. Rapid clean-outs are often threatening, worsen the disorder and do not serve to protect the children. Admitting hoarding when children and objects could be forcibly removed often underlies increased hiding. The more people become comfortable in their hidden world, the less they feel vulnerable and visible, and the easier it is to deny the consequences of the disorder. The children who surface into a life of their own carry residual wounds that are left unspoken (Chabaud, 2011).

A call for action: programme and policy considerations

People lose a right to privacy when vulnerable others under their care must be protected from substantial harm. Society can intervene for identifiable risks but cannot for undetectable ones. Suspicion of an imminent threat of serious harm to others must be well supported to override privacy rights. Risks in a hoarded home are often undetectable from the outside so means to ascertain and report risks are needed. Nevertheless, societal interventions must include a compassionate method to address the disorder without creating devastation and exacerbation of what already exists. Such methods will decrease the fear of discovery.

Examining the tremendous toll of hoarding disorder on people and resources (Frost, Steketee, & Williams, 2000; Nordsletten et al., 2014; Tolin, Frost, Steketee, Gray et al., 2008; Tolin, Frost, Steketee, & Fitch, 2008; Saxena et al., 2011) makes intervention strategies imperative. To protect the children, these strategies must build trust, reduce shame and stigma, be sensitive to the unique characteristics of each person and family and recognise their worth. Quickly discarding objects can hinder trust and make hoarding worse. Building trust starts with safety as the goal. Opening the door to a hoarded house by first emphasising safety could allow the eventual transformation of the meaning of objects in a person's life.

A harm reduction model focuses on safety rather than discarding per se (Marlatt, 1998; Tompkins, 2015). Implementing harm reduction relies heavily on a task force, a team of housing enforcement, protective services, health providers, organisers and agents who provide supplies, repairs and goods, all working in a coordinated fashion to accomplish the first goal of establishing safety. Social workers could oversee, coordinate and track interventions in the role of a case manager of task forces (Bratiotis et al., 2018). Management reduces cost, provides efficiency through coordination and builds trust with hoarding individuals.

Beyond safety, the long-term goal must include skills to better manage self, family and interpersonal relationships. Teaching people to self-assess their relationships with objects may provide greater objectivity and increased ability for self-care. Decreasing deficits in cognitive skills can enable confidence in approaching tasks. Family therapy can assist intra-family relationships including setting boundaries and reducing conflict. Skills to manage co-morbid ailments such as anxiety/panic, depression, trauma/stress, attention deficit hyperactivity disorders and autistic spectrum disorder and use of psychotropic medications, when appropriate, can enhance people's ability to progress. Relief from physical ailments through evaluation and treatment can increase energy to face hoarding challenges. Opportunities for self-expression and socialisation can reduce isolation, common in people with hoarding disorder. In all, helpful interventions will promote health, hope, self-worth, self-awareness, competence, motivation and gratifying interpersonal relationships. Maintenance and continual progress will require ongoing intervention and monitoring.

The UK mandates of the Care Act of 2014 extend the focus on adult safety to the overall well-being of adults. The 'HM Working Together to Safeguard Children of 2015', revised in 2018, extends governmental responsibility to the well-being of children. A significant section of these safeguards encourages the coordination of a team of multiple disciplines centred on children's care. A lead professional would establish trust with the child and family and coordinate other needed services. This holistic approach is optimised when it addresses the family's emerging problems and places the children's needs within the wider family context. These guidelines for assisting children make safeguarding them everybody's business and refer to necessities for safe and effective care, not only protecting children from maltreatment, but also prevention of circumstances that could impair their health or development.

The UK publication on Hoarding Disorder of the Southend, Essex and Thurrock (SET) Safeguarding Board (2016) makes children of hoarding parents a priority and is exemplary for establishing standardised procedures, references, definitions, guidelines and goals, including ones that pertain to child protection and early intervention. The Safeguarding for Hoarding Disorder requires addressing the needs of people with hoarding disorder and others at risk as a result of it, such as family members or carers. There are also guidelines for adults with hoarding issues who refuse assessment. 'Early Help' or early intervention for children and young people is considered optimal. Early intervention means involving individuals with emerging problems with appropriate support and timely coordinated services.

Reaching people who have early signs of hoarding disorder is optimal (Burton et al., 2015). Given its likely early onset

(Ayers et al., 2009; Grisham et al., 2006; Morris et al., 2016; Plimpton, 2009; Storch et al., 2007; Storch, Rahman et al., 2011; Tolin, Meunier et al., 2010; Zaboski II et al., 2019), usually, before most people have children, early intervention (Chabaud, 2014; Rozenman et al., 2019) could stall and address this otherwise burgeoning and enduring disorder. As such, many lives could be spared from dreadful hardships (Burton et al., 2015). Early intervention (Chabaud, 2014) can address co-morbid disorders (Burton et al., 2016; Frost, Steketee, & Tolin, 2011; Frost, Steketee, Williams & Warren, 2000; Hacker et al., 2016; Hall et al., 2013; Hartl et al., 2005; Lynch et al., 2015, Storch et al., 2007; Storch, Rahman et al., 2011). Co-morbid mental and health conditions add additional burdens to individuals, fuel hoarding and inhibit recovery from it.

With early intervention, people can learn interpersonal skills for gratifying socialisation and therapeutically address family issues that underlie attaching to objects instead of people. Early in the hoarding process, people can more easily learn skills for attention, management of anger and irritability, time management, organisation, categorisation, prioritisation, proper use of objects for creative and healthy self-expression, self-awareness and proper expression of emotions and needs. Professional organisers, coaches and therapists may best serve people during the early development of hoarding. School counsellors, physicians and mental health practitioners could assess people for hoarding tendencies and, if indicated, help them connect with appropriate services.

Assessment will vary depending on the age, mental conditions and life circumstances of the hoarding individual. Yet, developed assessment instruments, such as the Clutter Image Rating Scale (Frost, Steketee, Tolin, & Renaud, 2008), HOMES – A Multi-disciplinary Hoarding Risk Assessment (Bratiotis, 2011), and the Family Impact Scale for Hoarding (Nordsletten et al. 2014) could be a standard part of a full assessment of hoarded homes. Assessment of hoarding in children could be better standardised and developmentally appropriate, as in the Child Saving Inventory (Storch, Muroff et al., 2011; Soreni et al., 2018). Questions that screen children living in hoarded homes could be widely used, age appropriate and not trigger fear of disclosure. Some actions to help people who hoard and affected family members are to:

1. increase the availability of destigmatising information about hoarding;
2. increase funds for research that informs society and guides programmes and interventions;
3. fund and distribute information to make hoarding disorder and its risks commonly known;
4. start campaigns to change the public's understanding of hoarding and its relevance to all;
5. use non-stigmatising language in publications by avoiding the word 'hoarder' and replacing it with descriptors, such as 'people with hoarding behaviours, excessive cluttering or hoarding disorder';
6. use TV, Internet blogs, billboards, newspaper articles, posters and brochures to disseminate destigmatising information about hoarding and publicise resources for help;
7. get brochures to teachers and counsellors to reach out to children with early signs of hoarding disorder and/or who live in hoarded homes;
8. ensure that medical and mental health providers know red flags to hoarding disorder and children living in hoarded homes, and incorporate or develop additional appropriate screening measures that are integrated into full assessments;
9. distribute a uniform inspection checklist targeting child safety;
10. develop tools that social services can reliably and consistently use for interventions;
11. hold training workshops for every professional that might be called upon to assist families, children at risk and adults and youths who have hoarding tendencies or hoarding disorder;
12. start educational meetings and self-help groups at churches and schools;
13. develop community programmes that provide support for people with hoarding disorder and children in homes dominated by it;
14. develop a 'safe house' programme to transition families from a hoarded house to a safe house, and volunteer families or community facilities can provide safe houses for temporary shelter, while families receive therapy, and get training from organisers to manage a home free of clutter or excessive objects (Knerr, 2014);
15. connect people who hoard with concerned others, help them see that other people care and involve trained buddies who are working through some of their hoarding concerns;
16. work on legislation to protect families and communities from hoarding disorder;
17. encourage the use, refinement and development of treatment methods, such as harm reduction (Tompkins, 2011, 2015; Tompkins & Hartl, 2009), individual and group cognitive behavioural treatment (e.g., Muroff et al., 2014; Steketee & Frost, 2007; Tolin et al., 2014) and taught in the *Buried in treasures workshop* (Frost & Shuer, 2011), compassion-focused therapy (Chou et al., 2018, 2019) and treatment that utilises the whole family to facilitate progress (Chasson et al., 2014, Chasson & Siev, 2019).

Research by Drury and colleagues (2014) reports substantial functional impairment in people with hoarding disorder and in people who care about them, so recommend that treatments include related others, like children and spouses. Muroff and colleagues (2014) in *Group treatment for hoarding disorder: Therapist guide* outline treatment for hoarding disorder that includes the many components: education about the disorder, obstacles to progress, motivation enhancement techniques (Miller, 2002), cognitive behavioural therapy that targets problematic beliefs and associated emotions, skill development, methods for transitioning from hoarding to adaptive and rewarding behaviours and means for identifying and using people to accomplish progress in the home. Becca Belofsky and Lee Shuer, who co-founded Mutual Support Consulting, employ destigmatising language while delivering a group method to decrease cluttering behaviour and offer workshops in many countries, like Australia and the USA. Reducing stigma and shame, recognising the value in objects that enhance life and applying personal attributes to positive relationships with objects seem to be at the core of helpful methods. The current trend is to compassionately approach people with hoarding disorder without shaming and with caring (Chou et al., 2018, 2019; Chasson et al., 2018). Compassion must be used to guide, inform and build trust, but, alone, does not protect children from parents' hoarding. We cannot save every child, but we can curtail hoarding that causes neglect, abuse and home hazards and has a multigenerational impact.

Uncovering what psychologically bonds people to the hoarding process offers a gateway to the self and allows a release of hoarding and objects. People can respect and compassionately embrace their journey through trauma and distress (Tolin, Meunier et al., 2010).

The worthy self can be elevated as the object world is redefined; purpose, pleasure and self-definition can evolve beyond the confines of objects. This transformation can be fulfilled and sustained with skill development and reapplying existing skills to worthy pursuits. Skills for self-compassion and mindful awareness can promote self-worth and the ability to embrace, accept and respect emergent emotions while resilience is learned.

> Transformation is possible when people have the courage to encounter their unguarded and unprotected selves. We cannot recklessly strip away their armour or ravage their treasures. We must assist them to redefine deeper, sustaining, and life-promoting treasures that will eventually operate to protect them in previously unbeknownst ways. To allow the elaboration of self-definition, they have to discover what has permanence and substance beyond the existence of the hoarded objects and hoarding process. People who embark on this journey unprepared will collapse from the pain of an overexposed and vulnerable self. (Chabaud, 2011, p. 2)

It is crucial to make funds, education and services available to meet the needs of people affected by hoarding disorder. Parents of youths can be informed about the long-term impact of this disorder and the ways their children could be harmed. Media and publications can continue to alert and inform parents of the need for therapy and other resources. Brochures in all paediatrician offices are needed to educate and direct parents who struggle with hoarding and object management. Parents/caregivers can be encouraged to report their concerns to providers who can act as referral sources. Training to properly assess and address hoarding disorder must be in every educational programme for health practitioners. Organisations can raise funds for in-home services and be trained to therapeutically work through the hoard. Friends, family members and clutter buddies can be taught how to assist and not antagonise.

Currently, child protective services need increased staffing, training, funding and assistance from other social support systems to face the immense number of families in need of therapy, protection and interventions for hoarding concerns. Yet, advances in programmes, interventions and protection are being developed and used effectively in some communities (Bratiotis et al., 2013). Forcibly removing children, dividing siblings and placing children in foster homes is not the final answer. The protection of children must be guided by actions that decrease harm and increase opportunities for healthy developmental opportunities.

Children cannot be removed from parents with a diagnosable disorder unless it poses endangerment. Child endangerment as it relates to a psychiatric disorder is complex. Many disorders do not put families at risk and can be addressed with therapy and non-invasive social assistance. On the other hand, a disorder that puts children and dependents in danger will require forced interventions, which does not apply to competent adults who do not put others at risk. Competency is legally defined. Neighbours may be less at risk in rural communities in which houses are widely separated as compared to neighbours in urban areas where houses are close in proximity.

Is protecting children of hoarding parents at odds with efforts to assist the parents? No indeed – saving children from hazards of a hoarded home helps all involved in sustaining healthy human systems. After gaining entry to a hoarded home, parents must be informed of conditions of safety that are clearly defined and consistent across all public and social services. Safety must be efficiently accomplished with all facilitative resources. Children will need temporary placement, optimally with people they already trust, until this is accomplished. If a family does not have financial resources, services must be publicly funded to skilfully address safety concerns. Remediation of unsafe homes must be followed with consistent and long-term monitoring and guidance to maintain safety and eventually improve the disorder. Social services can be funded to provide in-home monitoring and referrals to help families to achieve a functional and beneficial family home. Children must be taught to be functional members of a healthier family and maintain a better home.

It is time for public health organisations to place life for children in severely hoarded homes on the list of hazards to their health and well-being. We need a worldwide campaign to increase awareness of the tolls of this disorder and develop methods informed by research for guiding whole families into health. Policy must focus on the desired targets and avoid unintended consequences. Disrupting an ailing family system must be couched within a guiding plan for recovery and growth. Extreme disturbance of any system could result in its decline, even to extinction. Compassion and awareness of the inner dynamics of a family system help guide planned and coordinated interventions and minimise negative results. Society cannot afford to ignore the consequences of hoarding disorder on children, dependents, adult survivors of hoarded homes, hoarding parents and the generations that follow. If society compassionately assists people with hoarding disorder and their children, the long-term human and financial savings will be immense.

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