Ethical Challenges in Treating Hoarding Disorder: Two Primary Care Clinical Case Studies

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Sound ethical decision making is essential to astute and compassionate clinical care. Wise practitioners readily identify and reflect on the ethical aspects of their work. They engage, often intuitively and without much fuss, in careful habits—in maintaining therapeutic boundaries; in consulting with experts when caring for patients who are difficult to treat or have especially complex conditions; in safeguarding against danger in high-risk situations; and in endeavoring to understand more about mental illnesses and their expression in the lives of patients of all ages, in all places, and from all walks of life. These habits of thought and behavior are signs of professionalism and help ensure ethical rigor in clinical practice.

Psychiatry is a specialty of medicine that, by its nature, touches on big moral questions. The conditions psychiatrists treat often threaten the qualities that allow human beings to be individual, autonomous, responsible, developing, and fulfilled. Furthermore, these conditions often are characterized by suffering, disability, and stigma, and yet individuals with these conditions demonstrate tremendous adaptation and strength. If all work by physicians is ethically important, then psychiatrists' work is especially so. As a service to *Focus* readers, this column provides ethics commentary on topics in clinical psychiatry. It also offers clinical ethics questions and expert answers to sharpen readers' decision-making skills and advance astute and compassionate clinical care in the field.

—Laura Weiss Roberts, M.D., M.A

Hoarding disorder, characterized by persistent difficulty discarding or parting with possessions, is newly included in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) and affects approximately 2%−6% of adults (1–3). The difficulty in discarding results from both the perceived need to save items as well as the distress experienced at the prospect of discarding them (1). As a result, individuals accumulate large volumes of clutter that interfere with their ability to use the rooms in their home for their intended purposes (1). Clutter in the home may create safety risks for the individual or others (e.g., falls, pest infestation, fire) or lead to the threat of eviction (4–6). Hoarding disorder can cause clinically significant distress and disrupt family and social relationships and other areas of functioning (1). Approximately 75% of individuals with hoarding disorder have a concurrent mood or anxiety disorder, most commonly major depression (7, 8). Hoarding disorder places a heavy burden on communities, thus identification and treatment of affected individuals is urgently needed (5). Early detection and referral by the primary care team can lead to successful treatment that prevents serious long-term consequences for an individual and his or her community. Current interventions include psychotherapy (9), pharmacotherapy (10–12), and community services (13); however, other than three randomized controlled trials (14–16), a strong evidence base is lacking.

Numerous challenges may impede prompt assessment and treatment of hoarding disorder. Some of these challenges have important ethical dimensions, such as balancing respect for individual autonomy with minimizing risk to the patient's health and well-being. Specifically, individuals with hoarding disorder are often reluctant to seek help; many hide their disorder because of embarrassment and shame about the condition of their homes and are fearful that they will be evicted. Limited insight (e.g., recognition of one's own symptoms with some appreciation of their impact on one's health and environment) may also affect initial presentation and ability to engage with treatment recommendations (17). For example, someone other than a health professional (e.g., a landlord or building engineer responding to a maintenance problem) may be the first to detect the clutter (18) and then involve the housing court or other officials rather than recommending medical evaluation. Alternatively, individuals may seek help from primary care providers (PCPs) but ask for treatment of comorbid conditions or the consequences of hoarding disorder (e.g., injury resulting from a fall) rather than for the disorder itself (8). When an individual has poor insight into the harm the disorder is causing for him- or herself and his or her neighbors, referral to social services (i.e., Adult Protective Services) may be necessary. In severe cases, a court-appointed guardian may need to be assigned to assist the individual with harm reduction strategies to avoid an eviction. A thorough risk assessment is critical and should involve inquiry into potential fire hazards, pest infestations, and effect on family members, particularly those most vulnerable (i.e., children, older relatives) (19). Another challenge stems from clinicians' countertransference (e.g., feelings of

anxiety or being overwhelmed) when working with individuals with hoarding disorder, which, if not identified, may manifest in suboptimal care. In the two cases that follow, we explore ethical issues that must be considered to ensure that individuals are treated with respect and their individual rights are protected.

Case 1

Mrs. W is a 69-year-old woman who lives with her husband in a large apartment complex. She has several medical conditions, including asthma, heart disease, and type 2 diabetes. She recently fell and injured her hip. Her PCP is concerned about her balance, because she has tripped and fallen several times in the past year. When asked how she fell, Mrs. W discloses to her PCP that she "wasn't looking" and tripped over books on the floor. Mrs. W describes feeling sad over the past month and endorses irritability, loneliness, and insomnia.

Her PCP refers her for a depression evaluation by a psychiatrist working as a consultant to the PCP in an integrated care setting. The psychiatrist introduces herself as a member of the interdisciplinary team and completes a diagnostic assessment of Mrs. W, who reports experiencing depression over the past month resulting from conflicts with her husband. They argue about the large volume of clutter in the home. She reports she does have a "bit of a problem with keeping things." Mrs. W and the psychiatrist discuss the state of her home, the amount of clutter, and her thoughts and concerns. The assessment indicates severe hoarding behaviors and depression related to hoarding. The psychiatrist is concerned about Mrs. W's general medical status and mental well-being, with specific concerns about future falls (trip hazards) and possible pest infestation.

During the consultation, Mrs. W states that she does not want the psychiatrist to disclose to her PCP the extent of her hoarding issues. She notes how embarrassed and vulnerable she feels about the amount of clutter she has. She becomes increasingly angry and upset about disclosing her hoarding difficulties to the psychiatrist and states that she does not authorize the psychiatrist to share information about the severity of her hoarding. The psychiatrist is unsure whether she can consult with the PCP because Mrs. W is demanding that information about her hoarding not be disclosed.

1.1 Which of the following next steps is most appropriate and in line with ethical principles?

A. Inform Mrs. W that her PCP needs to know about her hoarding behaviors for safety reasons. Disclose information about her hoarding behaviors to the PCP after she leaves the office.

B. Make no comment to Mrs. W's PCP or the interdisciplinary team members about her hoarding in view of her refusal to give consent. However, share information about depression with the PCP because depression was the focus of the consultation.

C. Tell Mrs. W about fall, safety, and fire risks and risk of eviction. Express concern about her decision to not tell her PCP about her hoarding.

D. Discuss with Mrs. W the drawbacks and benefits of her choice to not disclose information about hoarding to her PCP. Engage in conversation while adopting a nonjudgmental and compassionate stance. Inquire about whether Mrs. W is open to meeting with her PCP and the psychiatrist to discuss her concerns.

It is important to consider how providers approach talking with their patients about hoarding and the impact of hoarding behaviors. Most people with hoarding disorder are reluctant and embarrassed to disclose hoarding difficulties. One of the most effective ways to address clutter is by talking nonjudgmentally and compassionately with patients to build trust. In this case, the psychiatrist could calmly speak with Mrs. W about her concerns, thereby highlighting her role as an active, caring, and supportive member of Mrs. W's medical team.

Individuals with hoarding disorder are considered a vulnerable population because of their risk of eviction and homelessness. Although hoarding disorder's impact can be extensive, the shame felt by people who hoard often keeps them from disclosing the behavior to others (4). Gaining knowledge about hoarding disorder and understanding the ways hoarding can affect an individual's life (i.e., how it can have an effect on psychological, physical, medical, social, and occupational well-being) will aid clinicians in responding effectively. Increased knowledge can also guide the clinician's approach to consultation with colleagues and the patient's medical team when discussing cases.

After Mrs. W tells the psychiatrist she does not want the information about her hoarding to be disclosed to her PCP, Mrs. W abruptly walks out of the exam room. The psychiatrist follows Mrs. W, and both are stopped by Mrs. W's husband. He says to them, "The hoarding is completely out of control." He is concerned for both his and Mrs. W's welfare and health. He exclaims to the psychiatrist, "She needs help! I've been trying to get her help for years, and the clutter is only getting worse. We can't cook, use the stove, or shower anymore. We had a small fire in our apartment last week from an electrical problem."

The psychiatrist asks Mr. W to have a seat in the waiting room and finds Mrs. W's PCP. The psychiatrist describes Mr. W's concerns and discloses the information about the severity of hoarding. The psychiatrist expresses concern about the safety of Mrs. W and her husband and suggests setting up a meeting with the PCP, the psychiatrist, and Mrs. W.

1.2 The psychiatrist's response highlights the ethical principle(s) of

A. Limits of confidentiality
B. Respect for persons
C. Autonomy
D. Nonmaleficence
E. Both A and D

This scenario highlights the reality that hoarding also affects family members and the community. Mr. W's call for help can be a common reaction when family or friends feel desperate and have difficulty helping their loved one who struggles with hoarding. Family and friends can feel overwhelmed when searching for assistance for hoarding disorder or when their loved one with hoarding disorder refuses help. This can result in relationship conflicts, social withdrawal, and the inability to work (17, 20). To evaluate and anticipate potential ethical dilemmas for patients who have hoarding disorder, providers should increase their knowledge of hoarding disorder, identify at least one other professional who can serve as a consultant for potential ethical questions, and ensure that the informed consent agreement they have with their patients is both thorough and clearly explained. As the health risks associated with hoarding disorder become better understood, education and dissemination of hoarding disorder knowledge to medical providers is critical.

Case 2

Ms. B, a 30-year-old woman seeing her PCP for a routine visit, reports new shoulder tightness and occasional tension headaches. When asked about recent stressors, Ms. B reports arguments with her 70-year-old father about his safety in his home. Her father, an avid collector of stamps, coins, and antiques, has recently developed an insatiable appetite for all kinds of collections, buying items from flea markets and thrift stores. The collections, previously confined to the living room, are overflowing into the kitchen. Ms. B has been unable to convince her father to stop accumulating items; he does not see his behavior as problematic and says Ms. B is violating his right to collect. She states that she plans to call Adult Protective Services.

The PCP consults with the psychiatrist on the interdisciplinary team. Together, they encourage Ms. B to help her father get an appointment at their clinic for a full medical and psychiatric evaluation. They also convince her to reconsider calling Adult Protective Services.

2.1. The PCP's choice of action reflects the ethical principle of

A. Fidelity
B. Beneficence
C. Nonmaleficence
D. Limits of confidentiality
E. Both B and C

The diagnosis of hoarding disorder can be made only after a complete evaluation that considers a full differential diagnosis, including other neurological and mental disorders (e.g., brain tumor, dementia, depression, psychosis). Although Ms. B's father is correct in stating that he has the right to his possessions, this right must be weighed against the possessions' impact on his ability to care for himself and the safety and well-being of his neighbors.

After several months, the medical, neurological, and neuropsychiatric testing is completed. Taken together, the results indicate that the father has early stage frontotemporal dementia. The father accepts follow-up care for his dementia. The following week, Ms. B and her father meet with the psychiatrist. Although Ms. B's father is initially reluctant, over the course of several sessions, he agrees to a plan for managing the clutter that is based on a risk assessment. He can keep his collections, as long as he agrees to a weekly housekeeper appointment to keep the exits and floor clear and thereby minimize the risk of falls.

2.2. The psychiatrist's choice of action most strongly reflects the ethical principle of

A. Autonomy
B. Beneficence
C. Fidelity
D. Veracity

This harm reduction approach works for another year, until Ms. B's father fires the housekeeper and refuses to let anyone in the home. Ms. B's father becomes verbally abusive to his landlord after a routine check of the smoke alarms reveals his place is violating the building safety codes. The father then gets a written notice (i.e., a three-day notice to cure) from the landlord (which gives him three days to declutter his living space). The father misses all of his follow-up health care appointments and refuses to leave the home for several weeks. Concerned about his well-being, Ms. B calls for an ambulance. The ER doctor completes an evaluation and determines Ms. B's father no longer has decision-making capacity and is unable to care for himself and ensure his safety. Her father requires stabilization in the hospital and connection to social and mental health services.

This scenario highlights several important issues. First, clutter alone is not diagnostic for hoarding disorder. In fact, clutter can be a result of multiple psychopathological processes, and a careful assessment and evaluation is needed to rule out organic brain disorders (e.g., traumatic brain injury, infection of the central nervous system, brain tumor, cerebrovascular disease) or another disorder described in *DSM-5* (e.g., autism, schizophrenia or other psychotic illness, obsessive-compulsive disorder, depression) (1). It is also important to distinguish hoarding from normal collecting behaviors, which are a pleasurable pastime for some individuals (21, 22). Second, respect for individual autonomy should be weighed against minimizing risk to the patient's health and well-being. In this case, the father was given the opportunity to keep a majority of his items with a harm reduction approach. Only when he was unable to care for himself and demonstrated a lack of capacity for decision making was the father referred for a higher level of intervention. Regarding eviction specifically, individuals who are threatened with eviction because of clutter have the legal right to request accommodation because of disability from hoarding disorder. Consultation with a legal representative is recommended to protect the individual's rights in these cases.

Answers

1.1 The answer is D. Although the other answers may seem justifiable, none of those actions reflect the most tempered approach to clinical care. Even though Mrs. W's hoarding behaviors may be maladaptive to some degree (e.g., piles of books may cause additional falls, clutter creates discord between her and her husband), the information she provided does not indicate that she or her husband is in imminent danger. In this scenario, the psychiatrist should consider whether disclosing information about hoarding to the PCP would be likely to undermine Mrs. W's autonomy. The risks and benefits of breaching confidentiality need to be weighed with those of the therapeutic alliance and the potential for serious harm (e.g., medical, psychological, or legal problems). Disclosing information at this time without Mrs. W's consent could affect whether she seeks help for hoarding in the future. Answer D reflects altruism and respect for persons, as the psychiatrist listens to Mrs. W's concern that her information be protected. Unlike the other options, answer D demonstrates flexibility and problem solving with patients.

1.2 The answer is E. This case demonstrates the principles of confidentiality and nonmaleficence. This scenario poses a difficult situation in which the psychiatrist must weigh the limits of confidentiality against Mr. and Mrs. W's rights to privacy and confidentiality. The new collateral information indicates the level of risk—specifically health risks from fire, falling, and poor sanitation—is higher than previously thought,. The psychiatrist shares her concerns for Mrs. W's safety and well-being with Mrs. W's PCP. The psychiatrist has the duty to "first, do no harm," by protecting Mr. and Mrs. W from the potential risks posed by severe hoarding. In this case, the psychiatrist could consult with the PCP about ethical dilemmas (e.g., release of information for Mr. W, confidentiality), refer to the American Psychiatric Association ethics code, and seek additional consultation.

If Mrs. W is open to meeting with the psychiatrist and PCP, they could discuss their concerns surrounding safety and the desire to maintain her privacy, then develop a plan of action with recommendations and referrals (e.g., social work, hoarding disorder resources). Mrs. W's treatment will be aided by transparency and accountability from the medical team for continued progress in decluttering efforts. If there is no demonstrable progress, the medical team may need to involve Adult Protective Services because of her age and the risk involved. The primary objectives in a meeting with Mrs. W, the psychiatrist, and PCP could be jointly identifying ethical issues and developing recommendations. A plan of action would include steps to be taken to minimize risks posed by hoarding (e.g., referring Mrs. W to therapy or a support group, making an appointment for an exterminator).

2.1. The answer is E. Beneficence and nonmaleficence are key ethical principles in this scenario. Individuals must be offered a full diagnostic interview and risk assessment before a recommendation is made, because a cluttered living space may be a symptom of multiple conditions. Identification and treatment of underlying causes, rather than referral to service agencies, has the greatest likelihood of benefiting the patient and minimizing the harm of misdiagnosis.

2.2. The answer is A. Each patient's autonomy should be upheld to the extent possible. Individuals who have the capacity to make informed decisions or who are in no danger of harming themselves or others have a right to the particular level of clutter in their homes. In this case, although the father may have difficulty managing clutter, he is willing to accept third-party help to keep his environment safe.

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