TREATMENTS THAT WORK

Treatment for Hoarding Disorder

Second Edition

THERAPIST GUIDE

GAIL STEKETEE
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OXFORD

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About Treatments *ThatWork*™

Stunning developments in healthcare have taken place over the last several years, but many of our widely accepted interventions and strategies in mental health and behavioral medicine have been brought into question by research evidence as not only lacking benefit, but perhaps, inducing harm. Other strategies have been proven effective using the best current standards of evidence, resulting in broad-based recommendations to make these practices more available to the public. Several recent developments are behind this revolution. First, we have arrived at a much deeper understanding of pathology, both psychological and physical, which has led to the development of new, more precisely targeted interventions. Second, our research methodologies have improved substantially, such that we have reduced threats to internal and external validity, making the outcomes more directly applicable to clinical situations. Third, governments around the world and healthcare systems and policymakers have decided that the quality of care should improve, that it should be evidence based, and that it is in the public's interest to ensure that this happens (Barlow, 2004; Institute of Medicine, 2001).

Of course, the major stumbling block for clinicians everywhere is the accessibility of newly developed evidence-based psychological interventions. Workshops and books can go only so far in acquainting responsible and conscientious practitioners with the latest behavioral healthcare practices and their applicability to individual patients. This new series, Treatments *ThatWork*™, is devoted to communicating these exciting new interventions to clinicians on the frontlines of practice.

The manuals and workbooks in this series contain step-by-step detailed procedures for assessing and treating specific problems and diagnoses. But this series also goes beyond the books and manuals by providing ancillary materials that will approximate the supervisory process in

assisting practitioners in the implementation of these procedures in their practice.

In our emerging healthcare system, the growing consensus is that evidence-based practice offers the most responsible course of action for the mental health professional. All behavioral healthcare clinicians deeply desire to provide the best possible care for their patients. In this series, our aim is to close the dissemination and information gap and make that possible.

This therapist guide and the companion workbook for patients address the puzzling and difficult problem of hoarding and acquiring. This disorder, characterized by a profound inability to discard material items that are no longer useful and a compulsive urge to acquire unneeded or excessive possessions, can result in severe disruption of interpersonal relationships, threats to health, and even death in some extreme cases from the dangerous accumulation of "clutter." Estimates suggest this problem afflicts as many as 2 to 6% of the population, who seldom present for treatment until late middle age when, evidently, they have had sufficient opportunity to accumulate overwhelming clutter.

The treatment program presented in this updated therapist guide and accompanying workbook represents the latest research on treating hoarding disorder. This evidence-based program, created by world-renowned, widely acknowledged experts in the field Gail Steketee and Randy Frost, leads to substantial improvement in most patients. With the designation of hoarding as its own distinct disorder in the *Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), more people affected by this problem will be recommended treatment, and this timely update of the successful program will give many patients hope to reduce clutter, organize their lives, and restore a peaceful order in their homes.

David H. Barlow, Editor-in-Chief,
Treatments *That Work*™
Boston, MA

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Treatment for Hoarding Disorder

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Chapter 1 *Introduction to Hoarding Disorder*

Background Information and Purpose of This Treatment Program

The relationship people have with their possessions has a fascinating history and ranges from purely utilitarian to intensely emotional. The number of personal possessions owned by ordinary people has exploded in the last 50 years. For most people, their personal possessions provide them with a sense of security, comfort, and pleasure. However, if someone loses the ability to distinguish useful or important possessions from those that make life overly complicated, then the objects can become a prison. Almost all of us keep some things we don't need and don't use. When these unneeded objects impinge on our living space, we no longer want them and usually get rid of them. But for people who suffer from hoarding disorder (HD), this process is not so easy. For them, possessions never "feel" unneeded or unnecessary and trying to get rid of them is an excruciating emotional ordeal. For some it is easier to divorce a spouse, sever ties with children, and even risk life and limb. Although people with this problem are overly attached to their possessions, they actually derive very little enjoyment from using them. Rather, they collect for a future date that never arrives. Until then, the clutter prevents them from living normally. A major goal of this treatment is to recapture the positive role of possessions in the lives of people with hoarding problems. This manual is the culmination of more than 20 years of work on understanding hoarding and building an effective intervention to address its myriad components. The intervention program is the result of a treatment development project funded by the National Institute of Mental Health.

A comment on language and terminology is warranted here. We recommend avoiding language that some clients find stigmatizing. On TV and

most news programs about the problem, people who hoard are often referred to as "hoarders." Unfortunately, the term describes a person rather than a behavior and, in our view, should be avoided in working with clients. Indeed, sometimes clients object to the term "hoarding" itself and prefer "saving," "collecting," or "cluttering." Agreeing on terminology early in treatment can help form the bond of trust necessary to treat this problem. In line with this, clients who hoard also often object to references to their possessions that reflect the therapist's values rather than their own. For example, referring to objects as "junk" or "trash" will often result in an emotional reaction regardless of the objective value of the object. Try to use the client's own words or choose neutral ones like "your things" or "the items in your living room."

This intervention relies on collaboration between clinicians and clients to achieve a shared understanding of the client's hoarding problem. Although the 12 chapters in this manual suggest a sequence of intervention strategies, we do not provide session-by-session instructions but, rather, adopt a modular approach because it is difficult to determine in advance the order of interventions because of the many features that contribute to clients' hoarding symptoms. We strongly recommend that clinicians read all chapters before starting. After completing a basic assessment and case formulation, decide what aspects of hoarding to focus on first and what methods to use. Understanding clients' hoarding problems fully will help you empathize with their struggle to overcome very powerful emotional attachments and strong beliefs as they make steady, often uneven, progress toward the goal of ridding their homes of debilitating clutter.

This manual first describes hoarding in sufficient detail to enable clinicians to diagnose and understand the problem and answer clients' and family members' basic questions. We consider this crucial information to dispel misunderstandings about hoarding behavior before trying to provide effective intervention. The next several chapters prepare clinicians to conduct the intervention. Chapter 2 reviews the evidence base for treatments described in this manual, and Chapter 3 covers methods for assessing the problem, along with illustrations of several forms for this purpose. In Chapter 4 clinicians collaborate with clients to formulate a model for understanding how the hoarding symptoms develop and occur in real time. Chapter 5 addresses a major problem in

hoarding: ambivalence about change. It includes methods to enhance motivation, drawing from motivational interviewing strategies originally developed for substance abuse problems. Chapter 6 focuses on treatment preparation and planning to select intervention methods based on the case formulation.

The next four chapters cover the core behavioral and cognitive interventions for acquiring, organizing, and saving problems. Chapter 7 focuses on cognitive and behavioral methods for reducing acquiring. In Chapter 8 clinicians train clients in skills for making decisions and organizing possessions and how to solve problems that inevitably arise in this process. Chapter 9 covers practice methods to habituate discomfort while sorting, and Chapter 10 outlines cognitive strategies for restructuring automatic thoughts and problematic beliefs. Chapter 11 gives recommendations for dealing with comorbid problems and complications that are common among people with hoarding disorder. The final chapter (Chapter 12) reviews treatment methods and provides tips on preventing relapse. Throughout these chapters, we illustrate the use of various forms for use during assessment and intervention to gage client's symptoms and progress. Blank copies of these forms are available in the accompanying client *Workbook,* as well as on the Treatments *That Work*™ website at www.oup.com/us/ttw.

Hoarding Disorder Diagnosis

The first systematic study of hoarding was published in 1993 (Frost & Gross, 1993), and the first operational definition appeared shortly after that (Frost & Hartl, 1996). What followed was a tremendous surge in research on hoarding by a variety of research teams mainly in the United States and Europe (Mataix-Cols et al., 2010). Early conceptualizations assumed that hoarding was a subtype of Obsessive Compulsive Disorder (OCD), like checking or cleaning. However, subsequent research indicated that hoarding differed from OCD in critical ways. Consequently, investigators concluded that it was a distinct condition and proposed that it be defined as a separate psychiatric disorder (Mataix-Cols et al., 2010; Pertusa et al., 2010b). In May 2013 when the American Psychiatric Association published the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), hoarding disorder (HD) was

included as a separate diagnosis in the Obsessive Compulsive and Related Disorders chapter along with Obsessive Compulsive Disorder, Body Dysmorphic Disorder, Excoriation (skin picking), and Trichotillomania (hair pulling). The diagnostic criteria for HD include:

A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.

B. This difficulty is due to a perceived need to save the items and distress associated with discarding them.

C. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).

D. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).

E. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome).

F. The symptoms are not better accounted for by the symptoms of another DSM-5 disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Specify if:

With Excessive Acquisition: If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.

Indicate whether hoarding beliefs and behaviors are currently characterized by:

Good or fair insight: The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic.

Poor insight: The individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.

Absent insight (i.e., delusional beliefs about hoarding): The individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.

Several features of the diagnostic criteria are worth noting. First, difficulty discarding is the primary behavioral problem. Clutter, which is the first thing people notice in hoarding, refers to the condition of the home and is the consequence of the behavioral problem. Treatment must focus on changing the behavioral problems (difficulty discarding and excessive acquisition if it is present). Clearing and sorting the clutter can be addressed in this context. Addressing them outside the context of therapy (e.g., cleaning services, etc.) may change the condition of the home temporarily but will not address the behavioral problem and may create problems establishing a trusting relationship with the client.

The difficulty discarding must be persistent to qualify for the diagnosis, which rules out temporary difficulties (e.g., inheritance of possessions from deceased family members; a recent move to a new home). Further, the real or objective value of the possessions saved in hoarding is irrelevant. A common misconception about hoarding is that it refers only to the saving of worthless or worn out things. Hoarded objects vary in objective value and are not limited to what others would consider worthless. Many HD cases involved rooms full of new clothing and items with price tags still attached.

Criterion B refers to the perception of need on the part of the individual for the possessions. This is at the heart of the hoarding problem and understanding it is key to treatment. The nature of attachments to possessions in hoarding ranges from utilitarian to intensely emotional. Most people who hoard view their possessions as having sentimental (emotional), instrumental (useful), or intrinsic (aesthetic) value. These reasons for saving are no different from most people, but they are applied to a much larger number and wider range of possessions and

may be experienced more intensely. People who hoard are often able to discard some items, but the process of doing so is so elaborate and time-consuming that the number of newly acquired items easily exceeds removed ones so the home gradually fills with things. In subsequent chapters we outline the nature of these attachments and beliefs about possessions. The therapy will largely focus on these attachments.

Criterion C details the consequences of A and B—the accumulation of possessions and the congestion and clutter that goes along with it. Two things are important here. First, the clutter must occupy the active living areas of the home. If it is confined to an attic, basement, closets, or storage facility, then this criterion has not been met. Second, the clutter must substantially compromise the ability to use the space in the way it was intended. In other words, normal functions are difficult or impossible (e.g., eating at the table). A few caveats should be noted. If the clutter is not severe because there are other people managing the clutter, then the diagnosis is still warranted. The presence of clutter reflects, in part, a deficit in the ability to organize possessions (Wincze, Steketee, & Frost, 2007).

The potential impairments in HD are wide-ranging. At severe levels, HD can make the home unsafe. Fire danger is associated with the presence of large volumes of flammable material (e.g., newspapers, magazines), limited ability to move easily throughout the house, and blocked exits. The loss of life and cost of fires is considerably higher for those that occur in hoarded homes compared to non-hoarded ones (Lucini, Monk, & Szlatenyi, 2009). Hoarding can also result in infestation, squalid conditions, and health problems (Frost, Steketee, & Williams, 2000a; Norberg & Snowdon, 2013; Tolin, Frost, Steketee, Gray, & Fitch, 2008a). The quality of life in patients with HD is significantly impaired, especially in the domains of safety and living conditions (Saxena et al., 2011). Work appears to be impaired by hoarding as well (Tolin et al., 2008a). Family conflict and marital disruption characterizes the personal lives of people with HD (Tolin, Frost, Steketee, & Fitch, 2008b). Each of these areas needs careful assessment before beginning therapy to ensure that the most serious conditions are targeted first in treatment.

Several medical and mental disorders can result in hoarding behavior and must be ruled out for diagnostic purposes. Each of the conditions

mentioned in the diagnostic criteria E and F can result in hoarding and would preclude an HD diagnosis. For example, certain obsessions and compulsions can lead to the accumulation of objects but not qualify as hoarding. Contamination obsessions can result in the inability to touch (and therefore dispose of) objects believed to be contaminated. Similarly, checking compulsions required before disposing of objects are sometimes abandoned, resulting in accumulation of large numbers of objects. Material collected in such cases is often more bizarre and trash-like than in typical HD cases (Pertusa et al., 2008). It is not clear whether the intervention described here would work for hoarding behaviors that result from these conditions.

Acquisition Specifier

Excessive acquisition is not included as a core diagnostic criterion, but diagnosis of HD requires a specification of whether the hoarding is accompanied by excessive acquisition. Research on excessive acquisition in hoarding indicates that the vast majority of HD patients acquire possessions excessively (*see* Frost & Mueller, 2013, for a review). In various studies, the frequency of excessive acquisition in hoarding ranged from 60% to 100%. Among HD patients who deny excessive acquisition, most report having had problems with acquisition in the past (Frost, Rosenfield, Steketee, & Tolin, 2013). Some clients deny acquisition problems, but partway through treatment, these problems emerge when they stop avoiding places where urges to acquire are strong. Such avoidance behaviors take the form of avoiding store aisles, stores, particular streets, parts of town, or whole cities.

Two forms of acquisition are most prominent: compulsive buying and the excessive acquisition of free things. Compulsive buying occurs in a variety of contexts including retail, Internet, and local (i.e., tag or garage sales). Excessive acquisition of free things occurs with give-away items (e.g., promotions) and items left on the street, in trash cans, and in dumpsters. Stealing occurs in a small number of HD cases (Frost, Steketee, & Tolin, 2011b). Acquiring is often associated with positive feelings (even euphoria) that reinforce the behavior and make it difficult to curtail. Both current and past experiences with each of these forms of

acquisition must be carefully assessed along with any avoidance behaviors associated with them.

Insight Specifier

The second specifier concerns level of insight. Many people who hoard do not consider their behavior unreasonable (Frost, Tolin, & Maltby, 2010; Tolin, Fitch, Frost, & Steketee, 2010a), and this may be particularly true among the elderly (Hogstel, 1993; Kim et al., 2001; Thomas, 1997). A study of complaints made to health departments about hoarding indicated that less than one-third of those identified in the complaint willingly cooperated with health department officials, and only half recognized the lack of sanitation in their home (Frost et al., 2000a). A large sample study indicated that more than half of family members believed their hoarding loved one had no insight or was in fact delusional with respect to their hoarding behaviors. This lack of insight may also contribute to the high rates of dropout and poorer treatment outcomes observed for compulsive hoarding (e.g., Black et al., 1998; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999). This problem can be particularly troublesome for family members seeking help and for service providers.

Careful consideration of the nature of beliefs about symptoms is needed in hoarding cases. Pure insight (anosognosia—inability to recognize a problem) appears to characterize relatively few hoarding cases (Mataix-Cols, Billotti, de la Cruz, & Nortsletten, 2013). Several related phenomena can be mistaken for absence of insight. For example, overvalued ideation or beliefs about the importance of seemingly unimportant possessions can be interpreted as a form of insight problem. However, such beliefs are part of the symptom pattern in hoarding and should be dealt with accordingly. Also, people with hoarding problems appear to have strong defensive reactions to other people's attempts to remove their possessions (Frost et al., 2010). Such reactions can appear to indicate lack of insight as well. Regardless of the source of the insight problem, motivation to change is often compromised. Even those who seek help for their hoarding become ambivalent when faced with decisions about removing clutter. For this reason, Chapter 5 includes specialized interviewing techniques for motivational problems.

Hoarding disorder must be distinguished from other conditions that it may resemble (for a review see Pertusa & Fonseca, 2013). Research indicates that the distinction between hoarding and extreme collecting is easily made, although extreme collectors sometimes display similar behaviors with respect to acquiring (Mataix-Cols et al., in press; Nortsletten & Mataix-Cols, 2012). Similarly, the differential diagnosis with OCD is relatively easy to make (Pertusa, Frost, & Mataix-Cols, 2010b). Up to 20% of HD cases are comorbid for OCD symptoms that may need to be addressed separate from hoarding. Compulsive buying, an impulse control disorder, is present in the majority of HD cases. For treatment purposes, it is probably best to conceptualize this in the context of HD rather than as a separate comorbid disorder.

HD is associated with several other disorders that can complicate treatment. Up to half of HD patients meet criteria for major depressive disorder (MDD) (Frost et al., 2011b), and the accompanying low mood and low motivation may need to be addressed if these appear to interfere with progress in treatment. Attention problems associated with ADHD (but not hyperactivity) are also prominent in HD (Frost et al., 2011b; Tolin & Villavicencio, 2011) and can interfere with the ability to organize, work outside of the therapy session, and persist at tasks such as sorting and discarding. Social phobia and generalized anxiety disorder (GAD) occur in up to one-third of HD cases and may need separate attention (Wheaton & Van Meter, 2013). Social phobia can make it difficult for patients to marshal social support and may exacerbate the social isolation reported among elderly hoarding clients (Kim et al., 2001). Such clients may rely on hoarding to shield them from social interaction. Worry associated with GAD may make difficulty discarding worse. Assessment of these complicating comorbid conditions is important for planning the intervention and preventing relapse. Chapter 11 provides a variety of suggestions.

Hoarding is also associated with various personality problems (e.g., Frost, Steketee, Williams, & Warren, 2000b; Samuels et al., 2002), such as perfectionism, indecisiveness, dependency, and compulsive personality traits. We have also observed avoidant, schizotypal, and

paranoid traits among some of our clients. The treatment program outlined here includes cognitive and behavioral strategies to reduce perfectionistic standards and rigid rules for saving and discarding and to reduce dependency on others to make decisions. When clients exhibit paranoid personality traits, clinicians must work harder to gain clients' trust, and interventions move more slowly to accommodate these concerns.

Prevalence, Course, and Family Patterns

In 2007 when this treatment manual was first published, there were no good epidemiological studies to indicate the prevalence of hoarding. Our best guess at the time was that it afflicted 1% to 2% of the population. Now at least five different epidemiological studies have been conducted, and taken together, they suggest that the prevalence of hoarding is between 2% and 6% of the population (Bulli et al., 2013; Iervolino et al., 2009; Mueller, Mitchell, Crosby, Glaesmer, & de Zwaan, 2009; Samuels et al., 2008; Timpano et al., 2011). This makes HD one of the most frequent of the mental disorders.

Research on onset and course of HD suggests that it begins early (Grisham, Frost, Steketee, Kim & Hood, 2006; Tolin, Meunier, Frost, & Steketee, 2010c), often between ages 11 and 15 years and rarely after age 25 years, but the problem does not become serious for several decades. Most cases report moderate or severe hoarding by age 40 years with little decrease in severity (Tolin et al., 2010c). In some cases trauma precipitates the hoarding, usually at a later age of onset (Grisham et al., 2006). Hoarding disorder is associated with an increased frequency of adverse and sometimes traumatic life events, but not PTSD (Frost et al., 2011b).

Although several epidemiological studies have suggested that men suffer from hoarding problems more than women, the preponderance of evidence suggests no difference by gender (Steketee & Frost, 2013). People with HD are less likely to marry and more likely to divorce (Samuels et al., 2002; Kim et al., 2001). Clients who live alone in their own home may have difficulty with motivation to change their hoarding because no one in the home is encouraging them to change.

Hoarding appears to run in families (Samuels et al., 2002; Winsberg, Cassic & Korran, 1999), and there is growing evidence for a genetic component (Hirschtritt & Mathews, 2013). This suggests that many of those seeking help will have family members who also engage in (and likely condone) hoarding behavior. This has proved problematic for some clients when only one family member is interested in reducing hoarding behaviors whereas the other sees no reason to change and resents the intrusion of clinicians. Neuropsychological and neuroimaging studies have reported abnormal activity in orbitofrontal cortex, dorsal anterior cingulate cortex, and superior temporal regions, as well as performance deficits on tasks of planning, contingency learning, and sustained attention. These findings are consistent with clinical reports of decision-making problems in hoarding patients and warrant training in decision-making and other cognitive skills as described in Chapter 8.

Special Features

Occasionally, hoarding occurs in squalid conditions that constitute a serious public health problem that threatens occupants of the home (Norberg & Snowden, 2013). (*See* the squalor questions in Chapter 3.) In such cases, public health officials or other agencies may become involved. Another serious variant of hoarding is animal hoarding, defined as the accumulation of a large number of animals, typically in excess of 20, that are not intended for the purpose of breeding or sale (Ayers & Patronek, 2013). The owner fails to provide an adequate living environment for the animals, as indicated by overcrowded or unsanitary living conditions, inadequate veterinary care and/or nutrition, and the unhealthy condition of the animals. Even when they are clearly unable to provide adequate care, most people who hoard animals are reluctant to place the animals in the custody of others. Animal hoarding is often identified through complaints by neighbors to legal authorities such as animal control agencies. This manual is not designed to address animal hoarding, as there is currently limited research to indicate what causes this problem (e.g., Steketee et al., 2011) and how to treat it. For further information about animal hoarding, contact the Hoarding of Animals Research Consortium (HARC) at their website

www.tufts.edu/vet/cfa/hoarding and see the Angell Report (2006) published by this organization.

Treatment Program

The next chapter reviews the types of treatments (behavioral, pharmacological) that have been used for hoarding before development of the cognitive behavioral model and how successful these therapies have been. This is followed by a description of the cognitive behavioral model for understanding the hoarding disorder based on the symptoms described above. The CBT methods that result from this model have proven to be efficacious in research studies as indicated in Chapter 2.

Chapter 2 *Evidence-Based Treatment for Hoarding Disorder*

Development of Cognitive Behavioral Treatment (CBT) for Hoarding Disorder

The intervention program described here grew out of our work with individual clients studied intensively in single case and small group designs. The clients who received treatment exhibited moderate to severe hoarding behaviors and substantial comorbidity such as that described earlier, included major depression, attention deficit disorder, and sometimes problematic personality traits. Some were highly functional in their employment and social lives, but struggled to make headway with severe clutter that filled all living spaces and rendered the home useless for all but bathing and sleeping. Others who exhibited work, social, and family impairments responded to the intervention but sometimes with less overall improvement. Although we recommend that clients with severe symptoms be treated by more experienced clinicians who can field the range of personality traits and motivational problems often evident among those with HD, novice clinicians can deliver this treatment effectively (Turner, Steketee & Nauth, 2010) and can also play supporting roles with regard to coaching during home visits (Muroff, Steketee, Bratiotis, & Ross, 2012). Davidow and Muroff (2011) determined that people with hoarding problems wanted coaches (students, peers, and family members or friends) who were trustworthy and had good listening skills to help them organize their things.

Although the therapy content is somewhat similar to CBT methods for other conditions, in our pilot and wait-list control trials every fourth meeting occurred in the client's home, usually for extended periods of 1.5 to 2 hours. The chronicity of hoarding and the associated motivational difficulties have led us to conclude that work in the home is important to successful outcomes in most, although undoubtedly not all, cases.