

Hoarding with the Home Patient: Managing a Difficult Issue

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Maria O'Shaughnessy MSN,RN,CNN,CNL

DSM-5 DEFINITION

Hoarding disorder- code 300.3(F42)

1. Excessively saves items and the idea of discarding items causes extreme stress
2. Cannot bear to depart from any of their belongings
 - results in excessive clutter to an extent that *impairs functioning*
 - may create *health and safety risks*
 - more than collecting a little clutter
3. Living space not usable for the intended purpose

DSM-5 (Diagnostic and Statistical Manual of Mental Disorders 5th ed.)

People with Hoarding Disorder:

- rooms are stacked full with items
- hallways are difficult to pass
- sinks and tables unusable
- They may come to the attention of authorities because of health and safety concerns of their homes.
- Hoarders are uncomfortable inviting guests over and guests do not feel comfortable in the hoarder's chaos.



CASE STUDY

Donna 76 yr old, recently widowed, on peritoneal dialysis 3 years

Mary - 73 yr old sister, moved into home after death of Donna's husband

Dan - 42 yr old son of Donna lives in the home

Synopsis:

One year after death of husband, staff takes notice of the gradual decline in Donna's health, (alb 2.8), Physical appearance, showing up late, documentation is inconsistent, forgetfulness, and tension among family members. Mary is primary support but now irritable. Dan offers little physical and emotional support but expresses anger and frustration to the clinic staff.

Clinic social worker receives call from the Adult Protective Services - home "incompatible with acceptable living stands, given 2 weeks for cleanup with threat of legal action to Code Enforcement

- IDT meeting called, home visit made by RN and SW

Situation found

- Excessive accumulation of debris in and out of the home
- Impassable walkways within the home
- Unsanitary kitchen
- Bathroom with mold
- Yard was full of debris

RESOURCES

Social worker provides home de-cluttering agency resources.

Hoarding expert at local senior center provides staff in-service and additional local resources.

Clean-up begins but is halted by bad weather, family accusations of theft by cleaning service, and Donna's hospitalization for a pelvic fracture due to a fall. Discharge deemed unsafe in home's present state.

QUESTIONS TO CONSIDER

What ethical responsibility does the IDT have to ensure the home environment is suitable for therapy?

- Who defines suitable?
- Who defines clean and safe?
- Does the hoarding interfere with the treatment?
- Does fear of infection and injury drive the clean up?
- Clinic ratings?
- Infection rates?
- Reimbursement rates?



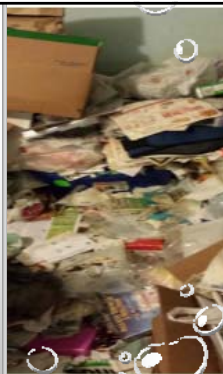
WHO ARE THE STAKEHOLDERS?

Direct vs. Indirect

- | | |
|---------------|-----------------------------|
| PATIENT | HOME THERAPY COMPANY |
| FAMILY | DIALYSIS SUPPLY COMPANY |
| PHYSICIAN | MEDICARE INSURANCE PROVIDER |
| NURSE | COUNTY HEALTH DEPARTMENT |
| SOCIAL WORKER | NEIGHBORS |
| DIETITIAN | |

WHAT IS THE ETHICAL ROLE OF THE HEALTH PROVIDER ?

- Bound by a mission to make life better for those with kidney disease – what are the parameters?
- Public safety – fire, neighborhood rodent safety, adult protective services guidelines
- Who is the primary concern? The patient!
- To what extent is the team responsible to treat the hoarding? How far should the home therapy team go with the hoarding situation?



RECOMMENDATIONS

- Direct communication with family
- Attitude of compassion
- Avoiding triggers of blame
- Promote sense of autonomy
- Safe therapy environment
- Address urgency to maintain housing

RESOLUTION

A professional clutter cleaner was employed. The family was disillusioned and terminated services. When injury occurred and faced with not being able to return home an out of town niece stepped forward.

De-cluttering was arranged, new carpeting, and acceptable access to the living quarters transformed the previously uninhabitable area to a clean, safe environment for performing home peritoneal dialysis.

Animosity among the family remained high. The county never pressed charges.

The doctor ultimately had the greatest influence upon continuance of therapy.

GOAL OF HOME THERAPY

Communicate – Be clear about the home environment and treatment parameters
Be straightforward and factual with information.

Avoid triggers of blame leading to judgement

Promote self-efficacy, respect autonomy, offer education and guidance in professional matters.

Advocacy- while not crossing boundaries into other medical issues not prepared to address.

Implement a policy of home inspection prior to initiation of therapy.

ETHICAL PRINCIPLES TO PONDER

ETHICAL DILEMMA – Conflict between 2 or more competing values exists.

DUTY –Do we have a *duty* to insist the home meets clinic policy for cleanliness?

Deontological duty states we are obligated to act within certain principles and rules regardless of the outcome.

Ethical principles protecting the patient –

BENEFICENCE – moral obligation to act for the others' benefit with the goal of preventing or removing possible harms.

NON-MALEFICENCE – directs us to avoid harm in the course of providing healthcare, *to do no harm* by protection from *avoidable* harm caused in the course of treatment.

WHAT WE LEARNED

Assessment prior to start of therapy can give you indication of home environment.
 Follow-up when situation calls for it.
 Make return visits!
 Prepare for and expect resistance.
 The hoarder may be too embarrassed and overwhelmed to take action.

Make referrals to psychologist if receptive.
 Watch for safety hazards in the home.
 Hoarding is usually triggered by an event.

TRY TO REMEMBER

- Avoid expressing feelings of disgust or disapproval.
- Be patient and supportive.
- Don't tell the person how they should feel.
- Develop trust, don't throw anything away without asking.
- Maintain focus.
- Set reasonable goals.
- Work in a targeted area, one small space at a time.
- Stop incoming items and help with removal from site.
- Use 3 categories for items – **Discard, Donate, Keep.**
- Devote a set amount of time each day for these tasks.
- Don't expect rapid results.







