

Hoarding to the heart's content: a case series and detailed case report of hoarding treatment in heart failure

Phillip Tully¹, Suzanne Cosh², and Bethany Wootton³

¹The University of Adelaide Faculty of Health and Medical Sciences

²University of New England

³University of Technology Sydney

May 11, 2021

Abstract

Hoarding disorder (HD) is characterized by an accumulation of possessions due to excessive acquisition of, or difficulty discarding possessions. Evidence demonstrates an increased cardiovascular response in patients with HD. Cognitive-behavioral therapy modifications are described for HD patients with heart failure to compensate for fatigability, syncope and falls risk.

Running title: hoarding treatment in heart failure

Hoarding to the heart's content: A CASE SERIES AND DETAILED CASE REPORT of hoarding treatment in heart failure

Phillip J. Tully^{1,2}

Suzanne M. Cosh³

Bethany M Wootton⁴

1. Heart Failure Support Service, Central and Northern Adelaide Local Health Network, Adelaide, Australia
2. Freemasons Foundation Centre for Men's Health, Discipline of Medicine, School of Medicine, The University of Adelaide, Adelaide, Australia
3. School of Psychology, University of New England, Armidale, NSW, Australia
4. Discipline of Clinical Psychology, Graduate School of Health, University of Technology, Sydney, NSW, Australia.

Correspondence to:

Dr. Phillip J. Tully

phillip.tully@adelaide.edu.au

Ph: +61 8 8313 0514

Fax: +61 8 8313 0355

Freemasons Foundation Centre for Men's Health

School of Medicine, Level 6 AHMS Building

The University of Adelaide, Adelaide SA 5005, AUSTRALIA

Manuscript word count: 1,860

Tables: 2

Figures: 0

Abstract

Hoarding disorder (HD) is characterized by an accumulation of possessions due to excessive acquisition of, or difficulty discarding possessions. Evidence demonstrates an increased cardiovascular response in patients with HD. Cognitive-behavioral therapy modifications are described for HD patients with heart failure to compensate for fatigability, syncope and falls risk.

Key Clinical Message: To ensure heart failure patients are involved in sorting/discarding tasks during cognitive-behavioral therapy for hoarding disorder, modifications are necessary to compensate for high fatigability and reduce the risk for serious adverse events.

Keywords: hoarding disorder; cognitive-behavioral therapy; heart failure; cardiomyopathy; case series;

BACKGROUND

Hoarding disorder (HD) poses unique challenges to health clinicians, community services, and health regulators alike [1]. This disorder is characterized by accumulation of possessions due to excessive acquisition of, or difficulty discarding possessions, resulting in clutter severe enough to cause emotional distress, impair functioning, and preclude the use of living spaces for their intended purposes [2]. The addition of HD to international psychiatric classification systems, distinct from obsessive-compulsive disorder (OCD), underscores the importance and topical nature of this complex disorder [3].

Emerging evidence indicates the importance of HD to cardiovascular health. Specifically, the prevalence of heart disease is significantly higher in populations with HD than those without this disorder [4]. Autopsy of 61 unexplained deaths in persons with HD indicated that heart disease accounted for 50% of sudden deaths [5], with severe coronary artery stenosis (42.4%) and myocardial replacement fibrosis (44.1%) common. Moreover, an in-vivo observational study during cognitive-behavioral therapy (CBT) showed that patients with HD demonstrated increased cardiovascular response when discarding personal possessions versus control items [6].

Cognitive-behavioral therapy is a frontline treatment for individuals with HD. A recent meta-analysis demonstrated that large effect sizes were seen on HD severity ($g = 0.82$) [8]. Contemporary CBT for HD focuses heavily on within-session and between-session sorting and discarding [9]. Other components of treatment often include skills training relevant to decision making and problem solving, motivational enhancement, emotional regulation training, cognitive change techniques, and reducing acquisition [9].

To the best of the authors' knowledge, no prior research has described the presenting psychiatric and cardiovascular characteristics, nor illustrated the therapeutic challenges faced when implementing CBT for HD in patients with severe heart disease. This is an important limitation to reconcile given the preponderance to heart disease in patients with HD, and the potential that sorting and discarding of possession, a key component frontline treatments for HD [11, 12], could lead to an increased cardiovascular response [6]. Therefore, the aim of the present study was to report on three patients with HD who were hospitalized for decompensated heart failure (HF). A detailed case-study is then presented to illustrate the therapeutic techniques, challenges faced, and suggested modifications when implementing CBT for HD in the patient population with comorbid HF.

Methods

Assessment

Here descriptive characteristics are reported for three patients with HD. These patients were recently hospitalized for decompensated HF. Typical HF symptoms include dyspnea, palpitation, and fatigue at rest or on

mild exertion, while decompensation requires immediate intervention, often consisting of diuretic medication to reduce pulmonary congestion and peripheral edema [13]. Each patient was referred to a psychologist as part of a HF self-management program (HFSMP). Written informed consent was obtained from each patient (#HREC/12/TQEHLMH/188).

Each patient underwent a HFSMP nurse screening assessment for depression, (Patient Health Questionnaire-9 items, PHQ-9), anxiety (Generalized Anxiety Disorder-7 items, GAD-7) and panic-attack (“*In the last 4 weeks, have you had an anxiety attack – suddenly feeling fear or panic ?*”) [14]. Patients underwent structured psychiatric interview with the Structured Clinical Interview for DSM-IV [15, 16]. Psychiatric diagnoses were verified by two senior clinical psychologists once per month. Other ratings included Global Assessment of Functioning (GAF) score and a Clinical Global Impression (CGI) – Severity and Improvement scale [17].

A detailed assessment of hoarding symptoms was conducted utilizing the Clutter Image Rating Scale (CIR) at the domicile [18]. The CIR provides a pictorial self-report of hoarding severity without the caveats of descriptive definitions of ‘clutter’ that may lead to unreliable estimates of hoarding behaviors. This nine-point visual analogue scale consists of a series of nine photographs of a room with increasing levels of clutter. Respondents select the picture that best represents the clutter in the rooms (kitchen, bedroom, living room). A score of 4 or higher indicates clinically significant clutter on the CIR [18]. The patient and psychologist each rated rooms on the CIR, with the psychologists’ ratings verified by a second rater using digital photographs (blinded to pre- and post-treatment).

Results

Case Series

The descriptive characteristics of each case including psychiatric comorbidities are outlined in Table 1. The medical history showed an ischemic etiology and poor cardiac functioning in each case. For Case 1-3, excessive acquisition was rated as yes, no, yes, while insight was rated as poor, fair and absent/delusional respectively. Alongside HD (27-40 year history), all patients met criteria for major depressive disorder and generalized anxiety disorder. No psychiatric history was documented in medical records for any case. None of the patients received psychotropic medication for management of HD or comorbid psychiatric diagnoses.

Case 1 Presentation

Background. Case 1 lived in Government housing with her youth aged child. They were facing eviction due to a state of squalor characterized by vermin, disrepair, unkempt premises, fire risk to neighbors, and health hazards imposed from food waste and soiled furniture. The patient’s possessions were unorganized throughout the domicile and yard, with one exception being the youth age child’s room. The patient collected items either because she thought they were valuable and/or usable in the future or for their sentimental value (reminders of a deceased family member). The onset of HD proximal to the death of a family member is consistent with trauma and grief etiology. There was no evidence of intrusive, repetitive, or ego-dystonic thoughts that are characteristic of OCD. For Case 1 the CBT intervention targeted excessive acquisition, focused sorting strategies (rubbish, recycle, donate, sell) and grief and loss (18 sessions, delivered every two weeks at the domicile) [11].

Barriers and modifications. Barriers to sorting tasks included poor self-management of HF and diabetes resulting in high fatigability and poor adherence to between-session homework tasks, further complicated by HF and diabetes hospitalizations necessitating digit amputation. Related barriers included difficulties with ambulation compounded by the state of clutter. Safety issues were also evident including soiled furniture and hazardous medical waste (e.g. used diabetic syringes). The patient received assistance from community support services and during CBT it became evident that community support workers were abetting acquisition behaviors.

In this treatment, the patient was responsible for all sorting and discarding tasks in line with the recommendations of Steketee and Frost [11], which was facilitated by the following modifications. Firstly, the patient was referred to an occupational therapist for assistance with ambulation (i.e. mobility walking

frame). Secondly, the delivery of CBT required pacing or interspersing sorting/discarding tasks in between cognitive-restructuring within sessions to compensate for high fatigability (cardiac nurse recommendation). Thirdly, during early CBT sessions, significant patient dizziness was observed resulting in premature ending of sorting/discarding tasks. It was hypothesized that postural changes (e.g. retrieving items on the floor) led to postural hypotension and transient hypoperfusion. Alternatively, dizziness may have been a hemodynamic side-effect of active diuresis or functional decline from recent hospitalization for decompensation. Thus, subsequent sessions utilized a raised platform for sorting/discarding tasks (i.e. temporary folding table) to reduce risk for serious adverse events including syncope and falls (cardiologist and occupational therapist recommendation). Finally, other modifications included extending the time length of each individual session (90-120 mins), an extended focus on exposure to discarding, and a reduction in the use of written materials and rating scales because of poor reading comprehension.

Outcomes

The pre-treatment and post-treatment outcomes for each case are outlined in Table 2. At post-treatment (after 18 sessions of CBT) Case 1 was ‘minimally improved’ based on the CGI, however the client had moved below a score of 4 on almost all of the room rating using both the client and clinician rated CIR, indicating the clutter no longer required clinical attention. The patient also showed moderate improvements in symptoms of generalized anxiety and on the GAF, but not depressive symptoms. At pre-treatment the patient was at risk of eviction, but at post-treatment the patient had not been evicted from the domicile. An audit of hospital admissions indicated readmission for HF/cardiovascular causes but not diabetes complications in Case 1.

Case 2 was rated as ‘much improved’ on the CGI post-treatment. On the CIR all rooms were rated below a 4 at post-treatment by both the client and the clinician indicating that the clutter was no longer at a clinical level. The patient also experienced significant reductions in symptoms of depression, moving from symptoms indicative of ‘moderately severe depression’ at baseline to ‘minimal depression’ at post-treatment [14]. A similar result was seen for symptoms of generalized anxiety, where the patient presented with ‘severe’ anxiety at pre-treatment and ‘minimal’ symptoms at post-treatment [19].

Case 3 declined CBT and did not complete post-assessment measures.

Discussion

This case series showed that three cases referred for mental healthcare as part of a HFSMP depression and anxiety screening initiative were incidentally found to meet criteria for HD. None of the HF patients with HD had any psychiatric diagnoses recorded in their medical histories despite comorbid major depressive disorder and generalized anxiety disorder, and the importance of depression to HF prognosis [20]. This finding highlights the importance of multi-modal evidence-based psychological assessment and the importance of a multi-disciplinary team approach for patients who are being treated for HF.

Across the three cases, one patient declined treatment, while the other two experienced modest improvements in HD symptoms. This finding is consistent with the wider literature where dropout rates can range from 13% [21] to 30% [22], and even after best-practice CBT treatment many patients with HD remain symptomatic despite reducing their symptoms significantly [8]. Reflecting this, multiple new directions for research are being investigated to enhance the efficacy of CBT for HD including adding a contingency management approach to treatment [23] and between-session internet-based clinician support [24] and such strategies may enhance outcomes in patients who have HD and comorbid HF or other cardiovascular diseases.

The case study highlights the importance of considering patient comorbidities and making case-informed modifications to best-practice treatment when working with individuals with HD, and how these modifications can support clients to engage in best-practice treatment for HD. Physical fitness and adherence to HF self-management [25] likely determines a patient’s capability for participation in sorting/discarding tasks that are critical in CBT for HD. Consequently, HF patients require pacing of sorting/discarding tasks to reduce fatigue, or other modifications. This parallels the practical assistance for patients with physical impairments

in a previous geriatric sample undergoing CBT for hoarding [26]. Indeed, modifications to standard CBT interventions in HF and other cardiovascular patients are poorly reported in the literature [27, 28], with most anxiety treatments designed for non-cardiac patients [29]. The paucity of anxiety disorder interventions in cardiovascular populations underscores the importance of further research and case-studies in this nascent field. Parallel research has shown that modifications to cognitive components of CBT in sub-samples with intellectual disability [30] and cognitive impairment [26] improve hoarding disorder treatment efficacy. Future research in this field is particularly important in HD, given the significant medical and psychiatric comorbidity seen in this population [4, 31].

In conclusion, CBT for HD appears moderately effective in the treatment of individuals with comorbid HF. However, the treatment necessitates several modifications to reduce risk for dizziness, syncope, and falls that clinicians should familiarize themselves with. The findings from this study may generalize to other cardiovascular conditions characterized by high fatigability or geriatric populations with postural hypotension and hypoperfusion. Future research in this field using larger samples is warranted.

Contribution details

Author 1 was responsible for concept, design, literature search, data acquisition, data analysis, statistical analysis, manuscript preparation, manuscript editing and manuscript review.

Author 2 was responsible for manuscript preparation, editing, and review.

Author 3 was responsible for manuscript preparation, editing, and review.

Acknowledgements

None.

Conflict of interest

Author's 1-3 declare that they have no conflict of interest.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Written informed consent was obtained from each patient (#HREC/12/TQEHLMH/188).

Human and Animal Rights and Informed Consent

This article does not contain any studies with animals performed by any of the authors.

References

1. Frost, R.O., G. Steketee, and L. Williams, *Hoarding: a community health problem*. Health Soc Care Community, 2000. **8** (4): p. 229-234.
2. American Psychiatric Association, *The diagnostic and statistical manual of mental disorders DSM-5*. 2013, Washington, D.C.: American Psychiatric Association.
3. Mataix-Cols, D. and L. Fernández de la Cruz, *Hoarding disorder has finally arrived, but many challenges lie ahead*. World Psychiatry, 2018. **17** (2): p. 224-225.
4. Tolin, D.F., et al., *The economic and social burden of compulsive hoarding*. Psychiatry Res, 2008. **160** (2): p. 200-211.
5. Darke, S. and J. Duflou, *Characteristics, circumstances and pathology of sudden or unnatural deaths of cases with evidence of pathological hoarding*. J Forensic Leg Med, 2017. **45** : p. 36-40.

6. Levy, H.C., A. Nett, and D.F. Tolin, *Discarding personal possessions increases psychophysiological activation in patients with hoarding disorder*. Psychiatry Res, 2019. **272** : p. 499-506.
7. Tolin, D.F., et al., *Cognitive behavioral therapy for hoarding disorder: A meta-analysis*. Depression and Anxiety, 2015.**32** (3): p. 158-166.
8. Tolin, D.F., et al., *Cognitive behavioral therapy for hoarding disorder: a meta-analysis*. Depress Anxiety, 2015. **32** (3): p. 158-66.
9. Tolin, D.F., et al., *CBT for Hoarding Disorder: A Group Therapy Program Therapist's Guide* . 2017: Wiley-Blackwell
10. Tolin, D.F., et al., *CBT for Hoarding Disorder: A Group Therapy Program Therapist's Guide*. 2017: Wiley.
11. Steketee, G. and R.O. Frost, *Compulsive Hoarding and Acquiring: Workbook* . Treatments That Work, ed. D. Barlow. 2007, New Yoprk, NY: Oxford Univesity Press.
12. Thompson, C., et al., *A systematic review and quality assessment of psychological, pharmacological, and family-based interventions for hoarding disorder*. Asian Journal of Psychiatry, 2017.**27** : p. 53-66.
13. Seferovic, P.M., et al., *Clinical practice update on heart failure 2019: pharmacotherapy, procedures, devices and patient management. An expert consensus meeting report of The Heart Failure Association of the European Society of Cardiology*. Eur J Heart Fail, 2019.
14. Kroenke, K., et al., *The Patient Health Questionnaire somatic, anxiety, and depressive symptom scales: a systematic review*. Gen Hosp Psych, 2010. **32** (4): p. 345-59.
15. First, M.B., et al., *Structured Clinical Interview for DSM-IV Axis II Personality Disorders, (SCID-II)* . 1997, Washington, D.C.: American Psychiatric Press, Inc.
16. First, M.B., et al., *Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Clinical Trials Version (SCID-I/P W/psychotic screen)* . ed. 2007, New York: Biometrics Research.
17. Guy, W., *ECDEU Assessment Manual for Psychopharmacology, Revised* , E. US Department of Health, and Welfare Publication (ADM) Editor. 1976, National Institute of Mental Health: Rockville, MD. p. 76-338.
18. Frost, R.O., et al., *Development and validation of the Clutter Image Rating*. J Psychopathol Behav Assess, 2008. **30** (3): p. 193-203.
19. Spitzer, R.L., et al., *A brief measure for assessing generalized anxiety disorder: the GAD-7*. Archives of Internal Medicine, 2006. **166** (10): p. 1092-7.
20. Atherton, J.J., et al., *National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand: Guidelines for the Prevention, Detection, and Management of Heart Failure in Australia 2018*. Heart, Lung and Circulation, 2018. **27** (10): p. 1123-1208.
21. Tolin, D.F., et al., *Efficacy and mediators of a group cognitive-behavioral therapy for hoarding disorder: A randomized trial*.J Consult Clin Psychol, 2019. **87** (7): p. 590-602.
22. Mathews, C.A., et al., *Randomised clinical trial of community-based peer-led and psychologist-led group treatment for hoarding disorder*. BJPsych Open, 2018. **4** (4): p. 285-293.
23. Worden, B.L., W.M. Bowe, and D.F. Tolin, *An open trial of cognitive behavioral therapy with contingency management for hoarding disorder*. Journal of Obsessive-Compulsive and Related Disorders, 2017.**12** : p. 78-86.
24. Ivanov, V.Z., et al., *Enhancing group cognitive-behavioral therapy for hoarding disorder with between-session Internet-based clinician support: A feasibility study*. Journal of clinical psychology, 2018. **74** (7): p. 1092-1105.

25. Lainscak, M., et al., *Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology*. European Journal of Heart Failure, 2011. **13** (2): p. 115-126.
26. Ayers, C.R., et al., *Novel treatment for geriatric hoarding disorder: an open trial of cognitive rehabilitation paired with behavior therapy*. Am J Geriatr Psychiatry, 2014. **22** (3): p. 248-52.
27. Shemesh, E., et al., *A randomized controlled trial of the safety and promise of cognitive-behavioral therapy using imaginal exposure in patients with posttraumatic stress disorder resulting from cardiovascular illness*. J Clin Psychiatry, 2011. **72** (2): p. 168-74.
28. Tully, P.J., A. Sardinha, and A.E. Nardi, *A new CBT model of panic attack treatment in comorbid heart diseases (PATCHD)*. Cog Behav Pract, 2017. **24** (3): p. 329-341.
29. Pardue, C.M., K.S. White, and E.V. Gervino, *The role of disease conviction: exploring its effects on chest pain and anxiety-related models of non-cardiac chest pain*. Journal of Clinical Psychology in Medical Settings, 2019. **26** (2): p. 131-141.
30. Kellett, S., H. Matuozzo, and C. Kotecha, *Effectiveness of cognitive-behaviour therapy for hoarding disorder in people with mild intellectual disabilities*. Res Dev Disabil, 2015. **47** : p. 385-92.
31. Frost, R.O., G. Steketee, and D.F. Tolin, *Comorbidity in hoarding disorder*. Depression and anxiety, 2011. **28** (10): p. 876-884.

Table 1. Descriptive characteristics of three cases of hoarding disorder with comorbid heart failure

Descriptive information	Case 1	Case 2	Case 3
Age range in years +	Mid-40's	Mid-50's	Mid-60's
Sex	Female	Male	Female
Ever or currently employed	No	Yes	No
Heart failure etiology	Ischemic, 6.5 year history	Ischemic, 8 month history	Ischemic, 55
Left ventricular ejection fraction	33%	27%	25%
New York Heart Association functional class	III	III	III
Renal disease	Yes	No	No
Diabetes	Yes	Yes	No
Previous myocardial infarction	Yes	No	Yes
Previous coronary artery bypass graft	No	Yes	Yes
Hypertension	No	No	No
Dyslipidemia	No	Yes	No
Obesity, body mass index kg/m ² >30	Yes	No	No
Current tobacco smoking	No	Yes	No
Psychiatric information			
Psychiatric history in medical records	No	No	No
Visited psychologist/psychiatrist previously	No	No	Yes (15 and
Psychotropic medication	No	No	No
Major depression	25 year history	6 month history	8 year history
Generalized anxiety disorder	38 year history	40 year history	35 year histo
Panic disorder	9 year history	No	9 year history
Social anxiety disorder	No	No	55 year histo
Post-traumatic stress disorder	No	No	Non-current
Obsessive-compulsive disorder	No	Yes	No
Hoarding disorder	27 year history	40 year history	35 year histo
Excessive acquisition	Yes	No	Yes

Descriptive information	Case 1	Case 2	Case 3
Insight	Poor	Fair	Absent/delus

+ The exact age of the three patients are de-identified to protect anonymity

Table 2. Pre and post treatment outcomes for three cases of hoarding disorder with comorbid heart failure

	Case 1	Case 1	Case 2	Case 2	Case 3	Case 3
	Pre	Post	Pre	Post	Pre	Post
Cardiovascular admissions, N (total LOS) ⁺	1 (10)	3 (38)	1 (4)	1 (28)	2 (27)	-
Peripheral vascular/diabetes admissions, N (LOS) ⁺⁺	1 (11)	-	-	-	-	-
Depressive symptoms (PHQ-9)	14	12	17	2	13	-
Anxiety symptoms (GAD-7)	17	5	21	1	12	-
Panic-attack screening question	Yes	No	No	No	Yes	-
Global assessment of functioning	5	15	45	55	25	-
Clinical global impression [§]	6	3	4	2	7	-
Clutter Image Rating Scale						
Kitchen – patient	3	1	2	1	2	-
Kitchen – clinician	4	2	2	1	8	-
Bedroom 1 ¶ – patient	7	2	3	1	2	-
Bedroom 1 ¶ – clinician	8	3	4	2	9	-
Bedroom 2 – patient	5	2	3	1	2	-
Bedroom 2 – clinician	7	3	4	2	9	-
Living room ¶ – patient	6	2	5	1	2	-
Living room ¶ – clinician	8	4	7	2	9	-
Hallway – patient	5	1	2	1	2	-
Hallway – clinician	7	1	3	1	8	-
Garage – patient	-	-	8	1	5	-
Garage – clinician	-	-	9	3	9	-

+ 6 months electronic hospital admission data pre-psychology baseline

++ 6 months electronic hospital admission data post-psychology treatment

§ Severity (pre) and improvement (post)

¶ Case 1's bedroom used entirely for storage; patient slept in the lounge room; Case 1's child's room not assessed (free from clutter); Case 3 declined treatment

GAD-7, Generalized Anxiety Disorder-7 items; LOS, length of stay; PHQ-9, Patient Health Questionnaire-9 items;

