Older Patients Living in Squalor

Lee SM, Martino E, Bismark M, Bentley R. Evidence to guide ethical decision-making in the management of older people living in squalor: a narrative review. Intern Med J 2022;52(8):1304–12.



"...[A] narrative review of existing research in older patients living in squalor..."

- 1. Clinical Context
- 2. Literature Search Strategy and relevant studies
- 3. Interrogation of Literature
- 4. Key findings examined
- 5. Conclusions
- 6. Critical Analysis
- 7. Specific Research
- 8. Future Directions

3.9 Million Australians were over 65 years of age (2018)

Most older people (95.3%) were living in households, with women twice as likely to be living alone as men.

Of all older people, 35.4% had a profound or severe limitation, 40.1% had a mild limitation of everyday activities.

In terms of assistance, 38.0% of all older people needed activities with everyday living

- 22.5% with healthcare
- 20.0% with property maintenance
- 16.0% with household chores

Up to 1 in 700 may be living squalor sufficient to represent a hazard to their safety

Literature Search

60 studies were identified by the literature search strategy, with an additional 7 find from review of citations and professional organisations.

Literature search conducted with search terms of:

- hoard, 'Diogenes Syndrome', squalor, clutter, elder, older
- person/adults/people, self-neglect, interven*, manag*

Mean of Participants > 60 years old

Studies excluded were:

- Conference Abstracts
- Publications with ≤ 3 participants
- Expert opinions or reviews

Diogenes Syndrome

Clarke et. al. (1975)

"Their homes were filthy on the outside-[with] peeling paintwork and dirty, often broken, windows with dingy net curtains serving as external markers to conditions within. Inside there was a characteristic strong, stale, and slightly suffocating smell." Cybulska (1998)

"It is high time to exonerate Diogenes of Sinope, a Greek philosopher of the fourth century BC...patients with severe self-neglect are certainly far from happy...often described as angry, suspicious, reclusive and buried under an abundance of inanimate objects, dirt and dust."

Interrogation

"The literature was coded inductively to map domain specific themes, with codes subsequently grouped based on the principlism framework. Such a coding approach allowed for a context-specific assessment of the research evidence in relation to each of the four ethical principles."

- 1. Cognitive profile and decision-making capacity
- 2. Natural trajectory of squalid living
- 3. Positive and Negative outcomes of interventions
- 4. Utilisation of resources by older people, impact on others, and justice

Cognitive Profile

"Studies of older adults with hoarding disorder found that most had executive dysfunction even if they did not meet the criteria for dementia, and many had poor insight and delusional thinking."

Ayers et. al. (2013); Prospective study of 40 patients with diagnosed Hoarding Disorder, compared to non-psychiatric outpatients

Ayers et. al. (2016); Uncontrolled study in 113 Hoarding disorder patients correlating hoarding severity to executive function

Schillerstrom et. al. (2009); Retrospective comparison of executive function between 63 patients referred to Adult Protective Services, and geriatric psychiatry outpatients

Tolin et. al. (2010); Family interview study of 558 insight questionnaires describing patients with Compulsive Hoarding

Natural History

"Several studies reported negative functional and health outcomes associated with squalor in older people." Ayers et. al. (2014); A prospective study of 65 patients with Hoarding Disorder, correlating hoarding severity to a functional assessment questionnaire

Clarke et. al. (1975); Early description of 30 patients living in squalor and associate medical comorbidities.

Darke & Duflou (2017); Study of autopsy findings of 61 patients suffering sudden or unnatural deaths with evidence of hoarding

Snowdon & Halliday (2011); Observational study of 173 patients referred to a psychiatry service with evidence of severe hoarding or clutter.

Treatment Outcomes

"Intervention options for squalor include case-management, cognitive behavioural therapy (CBT), compassion focused therapy, cognitive remediation and public sector responses."

Ayers et. al. (2011); A sample of 12 patients with compulsive hoarding treated with 7 weeks of manualised CBT

Ayers et. al. (2019); A secondary analysis of 44 patients with late-life Hoarding Disorder who underwent Cognitive Rehabilitation and Exposure/Sorting Therapy.

Chou et. al. (2020); A pilot study of compassion-focused therapy in Hoarding Disorder patients who had already received CBT.

Healthcare and Compassion Resource Use

"...compared with other psychiatric inpatients, older patients with squalor utilised more social services, stayed longer in hospital and were more likely to be discharged to dependent accommodations."

Franzini & Dyer (2008); Analysis of health-cost and utilisation of 131 patients with self-neglect referred to a geriatric multidisciplinary team by Adult Protective Services

Shaw & Shah (1996); Case-control series of 17 patients with "squalor syndrome" admitted to a psychiatric unit

Wilbram et. al. (2008); An self-referred interview study of 10 carer experiences of patients with Compulsive Hoarding

Conclusions

- Executive dysfunction and substance abuse are common to this patient population and decision-making capacity should be determined rather than assumed.
- Intervention is needed to reduce morbidity and mortality, and this may need to occur against the wishes of the older adult
- Older patients living in squalor have a detrimental impact on family and caregivers, as well as a wider healthcare burden

Critical Analysis

As a clinical presentation such patients are poorly described and represented in the literature and an up-to-date review is beneficial

A clear description of the clinical entity in question is not made

The literature as presented is very heterogeneous, and conclusions drawn are arguably too strong for the evidentiary backing

Case Descriptions

Snowdon & Halliday (2011), A study of severe domestic squalor: 173 cases referred to an old age psychiatry service

- > 80% of patients lived alone
- Dementia was the primary diagnosis in 26 -46% of all patients
- At one-year 47% remained at home, 32% had moved to long-term care, 9% had died

Shaw & Shah (1996), Squalor syndrome and psychogeriatric admissions

- 94% lived alone, compared to 71% of controls
- 50% had dementia, compared to 29% of controls
- Average length of stay was 140 day, compared to 52 in the control group
- 65% were discharged to a "more dependent" facility, compared to 31%

Autopsy Study

Darke & Duflou (2017), Characteristics, circumstances and pathology of sudden or unnatural deaths of cases with evidence of pathological hoarding

- 95.1% lived alone
- None had any medical intervention at time of death, and extensive hoarding impeded ingress by emergency services
- 75.5% died due to a chronic underlying pathology, 44.3% due to heart disease
- Less than 10% had been taking any medication for heart disease or diabetes

Health-Care Costs

Franzini & Dyer (2008), Healthcare costs and utilization of vulnerable elderly people reported to Adult Protective Services for self-neglect

- Compared to controls, 15% had a mental disorder, 3% in controls
- Alzheimer's disease 3%, compared to 0.9%
- Comparing patients with self-neglect before and after assessment:
 - 1.17 days length of average hospital stay, to 5.54 days (~ 4.5 days in controls)
 - o 18% utilised outpatient services, to 48% (63% in controls)
- No significant difference in healthcare costs after assessment, significantly less cost before referral
- Non-significantly less utilisation of services and medical care compared to controls

Future Directions

- How many older people are living in squalor?
- What do we mean when we refer to someone living in squalor, or hoarding?
- Are patients with a diagnosable Hoarding Disorder a distinct clinical entity to elderly patients with evidence of self-neglect and domestic "squalor"?
 - How are elderly patients with self-neglect different to the broader elderly population? What are the health-care cost compared to outcome measures?

References

- Chou C-Y, Tsoh JY, Shumway M, et al. Treating hoarding disorder with compassion-focused therapy: A pilot study examining treatment feasibility, acceptability, and exploring treatment effects. Br J Clin Psychol 2020;59(1):1–21.
- 2. Ayers CR, Dozier ME, Taylor CT, Mayes TL, Pittman JOE, Twamley EW. Group cognitive rehabilitation and exposure/sorting therapy: A pilot program. Cognit Ther Res 2017;42(3):1–13.
- 3. Ayers CR, Davidson EJ, Dozier ME, Twamley EW. Cognitive Rehabilitation and Exposure/Sorting Therapy for Late-Life Hoarding: Effects on Neuropsychological Performance. J Gerontol B Psychol Sci Soc Sci 2020:75(6):1193–8.
- 4. Ayers CR, Wetherell JL, Golshan S, Saxena S. Cognitive-behavioral therapy for geriatric compulsive hoarding. Behav Res Ther 2011;49(10):689–94.
- 5. Schillerstrom JE, Salazar R, Regwan H, Bonugli RJ, Royall DR. Executive function in self-neglecting adult protective services referrals compared with elder psychiatric outpatients. Am J Geriatr Psychiatry 2009:17(10):907–10.
- 6. Cybulska E. Senile squalor: Plyushkin's not Diogenes' syndrome. Psychiatric Bulletin 1998;22(5):319-20.
- 7. American Psychiatric Association., American Psychiatric Association. DSM-5 Task Force. DSM-5 Combo Set: Diagnostic and Statistical Manual And Desk Reference (ISBN-9780890425558 And 9780890425565). Fifth Edition. Washington, D.C: Generic; 2013.
- 8. Cybulska E, Rucinski J. Gross self-neglect in old age. Br J Hosp Med 1986;36(1):21–5.
- 9. Pavlou MP, Lachs MS. Could self-neglect in older adults be a geriatric syndrome? J Am Geriatr Soc 2006;54(5):831-42.
- 10. Shaw T, Shah A. Squalor syndrome and psychogeriatric admissions. Int Psychogeriatr 1996;8(4):669–74.
- 11. McDermott SC. Self neglect and squalor among older people: the ethics of intervention. 2007;
- 12. Australia Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings [Internet]. 2018 [cited 2022 Sep 13]; Available from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release
- 13. Wilbram M, Kellett S, Beail N. Compulsive hoarding: a qualitative investigation of partner and carer perspectives. Br J Clin Psychol 2008;47(Pt 1):59–73.
- 14. Franzini L, Dyer CB. Healthcare costs and utilization of vulnerable elderly people reported to Adult Protective Services for self-neglect. J Am Geriatr Soc 2008;56(4):667–76.
- 15. Ayers CR, Ly P, Howard I, Mayes T, Porter B, Iqbal Y. Hoarding severity predicts functional disability in late-life hoarding disorder patients. Int J Geriatr Psychiatry 2014;29(7):741-6.
- 16. Darke S, Duflou J. Characteristics, circumstances and pathology of sudden or unnatural deaths of cases with evidence of pathological hoarding. J Forensic Leg Med 2017;45:36–40.
- 17. Snowdon J, Halliday G. A study of severe domestic squalor: 173 cases referred to an old age psychiatry service. Int Psychogeriatr 2011;23(2):308–14.
- 18. Tolin DF, Fitch KE, Frost RO, Steketee G. Family informants' perceptions of insight in compulsive hoarding. Cognit Ther Res 2010;34(1):69-81.
- 19. Ayers CR, Wetherell JL, Schiehser D, Almklov E, Golshan S, Saxena S. Executive functioning in older adults with hoarding disorder. Int J Geriatr Psychiatry 2013;28(11):1175-81.
- 20. Ayers CR, Dozier ME, Wetherell JL, Twamley EW, Schiehser DM. Executive Functioning in Participants Over Age of 50 with Hoarding Disorder. Am J Geriatr Psychiatry 2016;24(5):342–9.
- 21. Clark AN, Mankikar GD, Gray I. Diogenes syndrome. A clinical study of gross neglect in old age. Lancet 1975;1(7903):366-8.