Diogenes syndrome: patients living with hoarding and squalor

Debbie Browne MBChB, MRCPsych, Rekha Hegde MBChB, MRCPsych

With a growing awareness that hoarding can be found in many psychiatric conditions, clinicians may recognise an increase in referrals for people presenting with hoarding. Here, the authors present three cases of hoarding behaviour stemming from different psychiatric conditions and discuss how hoarding can be managed.

Hoarding has captured the public imagination in recent years, with television programmes such as Channel 4’s ‘The Hoarder Next Door’ or TLC’s ‘Hoarding: Buried Alive’. The terms hoarding and Diogenes are sometimes used interchangeably but it is more useful to think of Diogenes as hoarding with self and environmental neglect, i.e. squalor.

With changes in legislation (such as the Mental Capacity Act 2005 and Adult Support and Protection (Scotland) Act 2007) and a growing awareness that hoarding can be found in many psychiatric conditions, including obsessive-compulsive disorder (OCD), schizophrenia, dementia, and others, clinicians may recognise an increase in referrals for people presenting with hoarding. In previous years this population may not have come to the attention of health services, due to the assumption that hoarding occurs in the absence of mental illness. Indeed this belief was reinforced by the absence of hoarding from the diagnostic criteria ICD10 and DSM IV, although it has now been coded for in DSM V.

Diogenes syndrome has over the years has been referred to as senile squalor syndrome and it can be understood as:

- Acquisition of, and inability to discard, objects that to others have (seemingly) little value – hoarding (sylligomania)
- Self neglect
- Environmental neglect (squalor)
- With refusal of help / isolation
- Seeming lack of concern by the person with regards to their situation.

**Epidemiology**

The accepted incidence of Diogenes syndrome is 0.5 per 1000 over the age of 65 years. Epidemiological data comes mainly from case series, which represents a poorly defined heterogeneous population. Furthermore, community health professionals are more likely to differentiate self-neglect, squalor, collecting and hoarding rather than define the disorder as Diogenes per se.

Men and women are equally affected, as are all socioeconomic groups. Those affected are often reported to be from a professional background, although this has been challenged. Independence, and social isolation have all been associated, as has older age, although young people may also be affected. Case series data suggest that 30-50% may have an underlying psychiatric diagnosis, including dementia, alcohol abuse, affective disorders, paraphrenia and subtle frontal lobe deficits not fulfilling diagnostic criteria for dementia.

**Background**

Macmillan & Shaw (1966) studied a population of individuals living in squalor and described the condition as a ‘senile breakdown’ of the standards of hygiene accepted by the local community. More than half of the sample was found to have a psychiatric disorder and an equal proportion presented hoarding personality traits.

Karl Jaspers called it the social breakdown of the elderly: he felt it was ‘a personality based abnormal emotional reaction development or adjustment disorder’. His view of this syndrome was that it represented a lifelong subclinical personality disorder, probably of a schizoid or paranoid type, that turns gradually into gross self-neglect and social isolation. This deterioration is precipitated by stressful life events, such as loss of a spouse or aging by itself, and is further aggravated by increasingly debilitating physical problems.

The term ‘Diogenes syndrome’ was first applied by Clarke et al. in 1975 to a case series of 30 elderly people with extreme neglect of their homes and personal health, and with the behavioural abnormality of hoarding rubbish.
Who was Diogenes?
Plato described Diogenes as ‘a Socrates gone mad’. He was a 4th century Greek philosopher also known as Diogenes of Sinope, or Diogenes the cynic, who advocated the principles of: ‘life according to nature’; ‘self-sufficiency’; ‘freedom from emotion’; ‘lack of shame’; ‘outspeakenness’, and ‘contempt for social organisation’.

The name of the syndrome is a reference to the reclusiveness and rejection of the outside world practiced by the philosopher who rejected convention and comforts in favour of a simple life of virtue. He reportedly lived in a barrel, naked and as ‘shameless as a dog’ or as a cynic (from the Greek word for dog). He also is said to have lit a lamp in broad daylight and said, as he went about, ‘I am searching for a human being’.

According to Marcos et al., Diogenes would have never been diagnosed as having his own syndrome, as the underlying motivation of the syndrome appears to be ‘a suspicious rejection of the world, rather than a desire to demonstrate self-sufficiency without material possessions’. This sentiment is shared by Cybulskia who said in 1998: ‘Some names appear to stick to syndromes or diseases like a proverbial glue, regardless of their being totally inappropriate.’ She felt that Diogenes was a misnomer and that Miss Havisham’s syndrome or Plyushkin’s syndrome (from Gogol’s book, Dead Souls) could equally apply.

Clinical approach
There is some clinical utility in the approach of Reyes-Ortiz who suggested a distinction between primary and secondary Diogenes syndrome depending on whether a mental disorder is present. The cases discussed here fall into either category.

For clinicians faced with a new case of squalor it is also useful to consider age. If the person is under 65 years old and has a 10-20 year history of hoarding it might be correct to assume they have primary Diogenes in the absence of mental illness. If, however, they are over 65 years old then the onus would be on the clinician to exclude organic illness as a cause of the hoarding / squalor. Again, the length of the hoarding is useful: if present for decades then it could be consistent with a primary Diogenes diagnosis but if emerging in someone with a previously acceptable level of personal and environmental care, a thorough cognitive and mental state assessment should be performed to exclude other diagnoses. This might take a few attempts to complete but a more aggressive approach is advocated.

With any clinical situation it is useful to ask oneself: ‘what are the risks?’ then ‘what can I do (within bounds of legislation)?’ and ‘what should I do?’ In some cases there is nothing that can or should be done, other than assessment and support.

Management will be multi-agency, involving joint working with social care workers and housing. The role of health services is to assess, diagnose and treat any health or mental health issue that may be either the cause of the current situation or a result of the situation. If there are issues of risk such as self-neglect, fire risk or vermin that could be managed under relevant mental health legislation such as the Mental Health Act or Adults with Incapacity, then it is important to do so. It is also important to assess the impact of the hoarding on other individuals in the household, especially if they are vulnerable, ie children, and social work may have a role in ensuring their wellbeing. If it is thought that the use of neither of these Acts is appropriate then social work may use legislation at their disposal such as the Adult Support Protection Act.

There are some situations in which the housing or environmental departments of local authorities may be the lead agency. Public health departments have powers to inspect properties and can issue statutory notices to force owners to clear their houses. If levels of cleanliness repeatedly fall below acceptable standards then the case can be referred to the Procurator Fiscal.

Case 1: Primary Diogenes
80-year-old female who describes a 30 year history of hoarding but no contact with Psychiatric services until October 2013.

An 80-year-old lady (Mrs A) who lives with her daughter, who is also a hoarder and who has her own mental health problems.

The patient was first referred to psychiatric services by her GP, after expressing suicidal ideation whilst in respite care. This had been precipitated by her granddaughter removing items from her home for the patient’s safety. Mrs A was upset by too much change, unhappy at being in respite and felt that she was losing control of her independence. The house was so cluttered with objects that only a narrow route from the front door into the house was available, with items stacked to the ceiling. The bedrooms were inaccessible, and the mother and daughter slept in chairs in the front room. This room only has two cleared spaces to sit in, the rest of the room being taken up with piles of random items.

Antidepressant medication was discussed, which the patient declined but she agreed to have contact with community psychiatric nurses and social workers.
Mrs A was reviewed over a number of months and was thought to be accepting of the removal of items that had been hoarded over 30 years. Her mental state had improved and she was discharged.

**Second contact**

She was referred again in October 13 by her GP with low mood, and stress about clutter in her home. She requested a move to sheltered housing and ‘wanted the clutter removed’. On assessment there was no evidence of self-neglect, depression or psychosis and she scored 28/30 on the Mini Mental State Examination.

**Third contact**

Mrs A had an admission to a general hospital with delirium. She was felt to be slightly elated and treated with risperidone, which was discontinued on discharge.

**Fourth Contact**

Concerns were raised by the general adult CPN involved with her daughter about the amount of money they were spending on house renovations. Mrs A was assessed and was not felt to be suffering from delirium or elated mood, and was thought to have capacity. She scored 80/100 on ACE III.

**Discussion**

This case history shows that assessments over a period of time revealed no psychiatric illness as a precipitant of hoarding behaviour; indeed illness had been precipitated by an unwanted attempt to clear the house and this is in keeping with the observation of Steketee that forced ‘clean-outs’ evoke strong negative reactions and hoarding continues after them.\(^{21}\)

Mental health services took a collaborative approach and were supportive of both mother and daughter. Given there were no issues of risk, the use of legislation was not relevant here. More recently the daughter has expressed a wish to deal with their hoarding and they are awaiting input from psychology.

For houses that are so cluttered they become a fire or vermin hazard local authorities can use the National Assistance Act 1948. This Act was introduced by the post-war Labour Government and established a specific duty on local authorities to provide residential accommodation for people in need together with a general duty to provide community services to disabled people. The Act also contains powers that are occasionally used to intervene in the lives of an individual person whom it is believed is creating an environmental hazard for others or whose best interests would be better provided for if he/she is admitted to hospital or a care home (and he/she is refusing to cooperate with such a proposed plan). However, these days it is rarely used as it has been superseded by more modern legislation, which are more Human Rights Act compliant. If these avenues have been exhausted or are not appropriate then each council should have an identified ‘Proper Officer’ who, with information from the social worker and environmental health officer involved, can make an application to the local magistrate’s court. The order, if granted, can last up to three months and after six weeks the person subject to the order can apply to have it revoked.\(^{22}\)

This law states that: for an order under section 47 of the National Assistance Act (1948) to be granted the person has to be:

- suffering from grave chronic disease
- aged and infirm
- physically incapacitated
- living in insanitary conditions
- unable to devote to themselves, and are not receiving from others, proper care and attention.\(^{23}\)

It must be borne in mind that forced clear-outs rarely result in a long-term solution to the problem and that the hoarding behaviour will persist and manifest itself again, requiring repeated clear-outs if the risk merits it. The process will be very distressing to the patient and ideally should be done with their consent and involvement.

For people whose hoarding is felt to be as a result of incapacity then consideration should be given to the use of the Mental Capacity Act (England) 2005 or the Adults With Incapacity (Scotland) Act 2000. (Please refer to Figure 1 for consideration of which legislation might be appropriate in certain situations.)

**Case 2**: Hoarding in context of frontal lobe stroke with predisposing personality traits.

A 75-year-old man who had a history of post-stroke mania and frontoparietal ischaemia, which had required a four week admission to a psychiatric hospital in 2011.

His elevated mood responded well to treatment and he was discharged home and followed up by CPN. On discharge he scored 92/100 on ACE III. A Functional assessment showed he was independent in his activities of daily living. He was mentally well on discharge although his house was described as cluttered.

He moved into new area and was seen as an outpatient only. A decision was made to gradually reduce his antipsychotic medication as he was well. However, he was seen in April 2014 and was felt to be slightly elated.

The doctor involved was concerned about the situation and
Figure 1. Decision tree identifying when to involve other professionals and/or agencies in the management of people with Diogenes syndrome and legislation that may be relevant to related issues.

MHA = Mental Health Act; MCA = Mental Capacity Act; AWI = Adults with Incapacity
decided to assess him at home with a mental health officer (MHO). On entry to the house access was limited by clutter with a narrow path into front room. Random objects were accumulated everywhere and piled high on the floor, tables and chairs. There was mouldy food sitting around. The kitchen was unusable with out of date with mouldy food everywhere and the rest of house was cluttered.

The patient’s mental state at interview revealed a euphoric mood, a feeling of wellbeing, increased appetite, increased spending (he thought he was rich), increased activity, increased libido, pressured speech, flight of ideas and poor insight.

The patient was thought to be suffering from a manic episode due to a reduction in his antipsychotic and was detained under a Short Term Detention Certificate, Mental Health (Care and Treatment) (Scotland) Act 2003.

He responded well to risperidone and his mental state improved. His house was cleaned in his absence and he returned home with CPN input. He continues to live in his house in a reasonable state of order.

Discussion

There was a suggestion from the personal history that the patient was predisposed to leading a cluttered life but that it was only after a frontal lobe stroke that it became unmanageable. Due to his lack of insight and the evident risk it was appropriate to use the MHA and that the clutter was a by-product of elevated mood. To date the patient remains euthymic and lives in an uncluttered state with no self neglect.

Case 3: Squalor and hoarding in the context of evolving frontotemporal dementia. This case highlights the importance of a good collateral history as one can put the presentation into context.

Mr L was a 90-year-old man unknown to psychiatric services before this referral. He lived alone and was unmarried with no children and his next of kin was a nephew.

The referral from the GP highlighted concern from both social workers and the workers at the Salvation Army lunch club, which Mr L normally attended daily. He was described as increasingly confused and dishevelled. He had been found wandering and brought back to his house by the police. The GP had tried to visit on a number of occasions but the patient was never in as Mr L was usually out on bus trips. On the day of referral the GP had been able to gain access and described the house as very malodorous and soiled with urine and faeces.

Mr L was disoriented in time and could not retain the GP’s name. He became irritated by questioning and repeatedly said he was fine and that he wanted to be left alone. He maintained he did his own shopping and cooking although the kitchen looked unusable with lots of empty marmalade jars. The GP’s opinion was that he was suffering from a dementing process and was posing a risk to himself but was not detainable and did not wish intervention.

A CPN tried to assess Mr L at the Salvation Army lunch club: people at the club were able to tell the CPN that Mr L had previously worked as a manager in a utility firm and had attended the local Salvation Army club for lunch daily for last four years. They had noticed a decline in his personal appearance and hygiene with weight loss, and his attendance had become sporadic. Bus drivers had turned him away due to his malodour. The police had found him asleep in a bus shelter on one occasion. The nurse tried to speak to Mr L and to assess him but he refused to speak to her and tried to leave, and while speaking to her he soiled himself. He was very malodorous and neglected.

Arrangements were made to assess the patient at home the next morning with a mental health officer.

Collateral history from Mr L’s nephew revealed that over last couple of years, and particularly the last six months, there had been a decline in the patient’s personal care, and that his house was unclean with unwashed bed sheets. There was no heating and he seemed unable to use the fire they had bought him, nor was he able to use the cooker or microwave. The nephew also felt his uncle did not recognise him.

The next day, services were informed that Mr L was in emergency respite having been taken there overnight by the police who had been concerned about him. They had attempted to take him home after finding him in the city centre where had had been sitting still for two and a half hours on a bench in the heat. On attending his house they found flies, mice, no electricity, no heating, faeces in a bag with used toilet paper all over the house and no food, with cupboards full of unused medication.

The assessing doctor found him smiling, cooperative, and very hungry. He was disoriented in time and place and did not know his own address. He thought his sister was still alive (she had passed away five months previously). He lacked any insight into his situation or the concerns people had about him.

It was felt that he needed inpatient assessment for physical and mental health reasons. In consultation with the MHO the decision was made to detain him using the MHA.
On admission, his clothes needed washing three times, his nails were in urgent need of chiropody, and his scrotum was enlarged and pustular. His admission bloods showed: eGFR 15; urea 32; creatinine 345, and CRP 147. As a result, he was transferred to the general hospital for investigation and treatment.

A CT scan done on transfer showed moderate global cerebral atrophy and severe atrophy of bilateral anterior temporal lobes, which was worse on the left side. These findings would be suspicious for frontotemporal dementia. Volume loss of the hippocampi was also noted and mild periventricular low attenuation was in keeping with microvascular disease. Although he responded well to IV fluids and antibiotics Mr L unfortunately died seven days later from cardiac arrest.

Discussion
With a full collateral it became clear that there had been deterioration in this man’s functioning and that his insight was impaired. He could have been managed under Section 47 AWI but as he physically improved he was less inclined to stay in hospital, therefore continued detention under MHA was appropriate.

Management

Assertive engagement and CBT
If the patient is willing to engage with treatment the approach best used is that of cognitive behavioural therapy (CBT), as the evidence base for pharmacological intervention is small and focuses on the use of selective serotonin reuptake inhibitors (SSRIs) for compulsive hoarding. Steketee and Frost, who have developed a CBT approach to the situation, hypothesise that: ‘Hoarders tend to use their collection of clutter as a form of comfort and security, with deep emotional investment coined as ‘hypersentimentality’; these individuals fear the grief-like emotions that would come with the disposal of clutter’. Maier also thought it was important to understand the individual’s intentions and attachment to the hoarded objects. He thought that subjects fell into two groups: those for whom the hoarding was a symptom and that any attempt to discard objects would result in distress, ie primary Diogenes syndrome, and those for whom the hoarding was a symptom and that the objects themselves had no emotional significance, ie secondary Diogenes syndrome.

Understanding the CBT approach
The intervention developed by Steketee focuses on four main problem areas:
- Vulnerability factors
- Beliefs and attachments
- Positive and negative emotions
- Hoarding accumulation and inability to discard.

The psychological approach involves an average of 26 sessions held on a weekly basis (range 15-30 depending on patient need) spread over 6-12 months. Ideally every fourth session is held at the patient’s house. Motivational interviewing aimed at addressing ambivalence and poor insight takes up part of several sessions, especially early in treatment.

The cognitive-behavioural component focuses on decreasing clutter, improving decision-making and organisational skills and strengthens resistance not to accumulate items. Cognitive restructuring addresses the individual’s obsessive fears with regard to discarding objects. This involves working with the anxiety of letting go of something that feels important. Patients learn to conceptualise their hoarding in terms of problems with anxiety, avoidance and information processing.

Progress can be assessed by using the Hoarding Scale and the Clutter Image Rating Scale.

Pharmacotherapy
To date, there have been no large randomised controlled trials to guide pharmacological treatment of primary Diogenes syndrome. SSRIs may be clinically useful; however, most of the data are from small trials involving patients with obsessive compulsive disorder have symptoms of hoarding, and not primary hoarding per se. At best, SSRIs are likely to be only partially effective in patients hoard with obsessive–compulsive disorder.

There have been a few small, open-label uncontrolled trials in primary hoarding patients. In one open-label study comparing primary hoarders to non-hoarding OCD patients, paroxetine showed similar response rates between the two groups, suggesting benefit from SSRI medication in patients who hoard. A similar small open-label study of 24 patients suggested extended-release venlafaxine may be effective for the treatment of hoarding disorder and was well tolerated. Authors of a small case series which examined the effectiveness of methylphenidate in patients with significant hoarding. However, only 2 out of 4 patients in the series demonstrated benefit, and the results were modest. So far, trials examining the effectiveness of pharmacotherapy in this patient group are small and unblinded – clearly there is a great...
Diogenes syndrome

Case notes

Dr Browne is a Consultant in Old Age Psychiatry, NHS Forth Valley and Dr Hegle is a Consultant in Old Age Psychiatry and Honorary Clinical Senior Lecturer at Leverndale Hospital, Glasgow.

Acknowledgements

With thanks to Professor Graham Jackson UWS, and Dr Damian Lynch, Consultant in Old Age Psychiatry, Lanarkshire, for their input.

References

20. https://www.glasgow.ac.uk/PublicHealth
22. https://www.westsussex.gov.uk/idoc.aspx?docid=f1dda48f-1ce4-43ee-a667-540570021ec1&version=1

Conclusion

If left alone, people suffering from Diogenes syndrome have an increased mortality with a 46% five-year death rate, 32 most likely due to non-engagement with services and poor compliance with treatment for concurrent physical illness.

Assessment is often prolonged and should involve a multi-agency approach. Clinicians should be aware of the association between hoarding and mental illness and the assessment process should be one of exclusion, using relevant legislation if appropriate.

CBT is still the most effective treatment for hoarding with a small group of compulsive hoarders benefiting from SSRIs.

www.progressnp.com