

REVIEW ARTICLE

“Diogenes Syndrome” Revisited

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Abstract

Diogenes syndrome refers to a condition with distinct self hoarding behaviours, severe self-neglect, filthy personal appearance and surroundings and social isolation. A broad range of co-morbidities exist, from Parkinson’s disease and frontal lobe dementia to learning disability, schizophrenia, depression and obsessive compulsive disorder amongst others. Recognition of the condition is important as it helps to individualize treatment plans to includes pharmacotherapy, cognitive and behavioural strategies within a safe environment were appropriate (German J Psychiatry 2009; 12: 38-44).

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Introduction

The term Diogenes syndrome was first applied by Clark et al. (1975) to old people who live in conditions of squalor. It was, however MacMillan et al. (1966) who conducted the first thorough investigation. They called the syndrome “senile breakdown”. Subsequently it has been referred to as “social breakdown syndrome” by Radebaugh et al. (1987) “senile recluse syndrome” by Post et al. (1982) and “litter hoarding syndrome” Jürgens (2000). Klosterkötter et al. (1985) used the term “Diogenes syndrome”. The syndrome is named after the 4th century BC recluse leader of ‘the Cynics’, Diogenes of Sinope, who gave up all comforts in life and took to begging for food and living in a tub or barrel.

Many authors have expressed concerns over the appropriateness of the term Diogenes syndrome (Cybulska et al.; 1986) stating that these people do not live as Diogenes chose to. Drummond et al. (1997) went as far as to describe it a ‘load of rubbish’. In coming to this conclusion they highlighted an association with Obsessive-Compulsive Disorder

and claimed that there was little evidence to support it as a syndrome in its own right. However, they reported a poorer prognosis in those with OCD and features of neglect. Others have argued that Diogenes chose to live the way he did, and that there is not enough evidence to say that individuals with the diagnosis make such a choice (Reifler 1996).

The estimated annual incidence is 0.5 cases per 1000 (Clark et al. 1975; Macmillan et al. 1966; Wrigley et al. 1992) aged over 59, which suggests a sizeable number of cases and a significant social and medical problem. A recent study in the Greater Dublin area highlighted the difficulties encountered when dealing with this issue (Hurley et al. 2000). It is not only elderly people suffer from this condition: 30.9% of their selected sample was below 65 years of age. This is in keeping with other studies (Cooney et al. 1995; Drummond et al. 1997; Vostanis et al. 1992). As is the finding that majority were females and most (72%) lived alone (Hurley et al. 2000; Steketee et al. 2001).

There are many case reports, a few case series, community surveys based on lists obtained from social services departments (Halliday et al. 2000) and a few reviews (Cooney et al.

1995; Robben 1991). There has however not been a systematic literature review. Problems with defining criteria are limiting factors in doing a systematic review.

The aim of this study were (1) To identify in relevant databases for any references to terms linked to “neglect” and “Diogenes syndrome”. Attempts were made to include diagnostic, treatment and human rights issues by including relevant search words along with the key terms, and (2) To identify and evaluate the evidence base for management of this condition.

Methods

The following databases were searched: EMBASE, PSYCHINFO, PSYCHLIT, MEDLINE, Cochrane, and Social Sciences Citation Index. The terms used for the search were: Diogenes; self-neglect; treatment of self-neglect; Human rights and self-neglect; senile squalor; social breakdown; litter hoarding; management of self-neglect; frontal lobe syndromes and self-neglect; obsessive compulsive disorder and self-neglect/squalor; paranoid schizophrenia and self-neglect/squalor. Abstracts, papers and chapters published in English language were included in the review. The authors also hand searched for cross references from published literature.

Case reports were perused to identify what criteria used, differential diagnostic issues and possible co morbidities. Case series were assessed to see how they were conducted, what methods were used, interventions by nature, duration of treatment and outcome criteria including general and specific morbidities.

Results

The searches identified 186 references in MEDLINE, 30 on EMBASE, 28 on PSYCHINFO and PSYCHLIT and nothing on the Cochrane databases. The Social Sciences Citation Index showed 27. Many studies were cited in more than one database.

Diagnostic criteria and distinction between related conditions and classification

Diogenes syndrome and equivalents have been widely mentioned in psychiatric literature over the past fifty years (Clark et al. 1975; Radebaugh et al. 1987; Wrigley et al. 1992; Townend 1957) along with reports in the lay media about mentally ill people living in appalling conditions. The presen-

Table 1. Diogenes Syndrome: Descriptive terms used by various authors

Symptoms	References
Severe degree of self-neglect	Clark et al. 1975; Klosterkötter et al. 1985; Wrigley et al. 1992; Williams et al. 1998
Domestic squalor	Clark et al. 1975; Klosterkötter et al., 1985; Wrigley et al. 1992; Ngeh JK. 2000; Williams et al. 1998
Social withdrawal	Clark et al. 1975; Wrigley et al., 1992; Ngeh 2000; Williams et al. 1998
Sylogomania (collecting/hoarding rubbish	Clark et al. 1975; Hurley et al. 2000; Ngeh 2000; Williams et al. 1998
Refusal to accept help	Clark et al. 1975; Hurley et al., 2000
Above average intelligence	Clark et al. 1975; Klosterkötter et al. 1985; Hurley et al. 2000
Aloofness	Klosterkötter et al. 1985
Emotional lability	Clark et al. 1975; Hurley et al., 2000
Verbal/physical aggression	Klosterkötter et al., 1985; Hurley et al. 2000
Suspiciousness	Clark et al. 1975; Klosterkötter et al. 1985; Hurley et al. 2000

tation, although often similar, has features that raise questions about the possibility of co morbidity (Clark et al. 1975). Most studies described the following features: poor personal hygiene, hoarding of litter, very poor surroundings (filth around and or in the house), and resist offers of help, social withdrawal and shameless attitude (Reyes, 2001).

A review (Cooney et al. 1995) examined those studies that outlined various management strategies. Neglect of personal care and a filthy environment are accepted as features of Diogenes syndrome but Diogenes should not be equated with self-neglect (Dick 2006). Neglect can be a result of severe physical disability or other issues/problems unrelated to Diogenes syndrome. In another review (Reyes 2001), self-neglect, domestic squalor, social withdrawal, sylogomania (hoarding of rubbish), and refusal of help are stated as the main characteristics.

It is important to distinguish this syndrome from OCD (Drummond et al. 1997). Individuals with the syndrome may also have suspiciousness and aggression (Hurley et al. 2000) and are notoriously difficult to treat as they refuse any form of intervention (Hanon et al. 2004).

Table 3. Conditions associated with Diogenes Syndrome

1. Psychiatric diagnosis preceding self-neglect	
a. Non-progressive cerebral disease, chronic alcoholism	Macmillan et al., 1966; Snowdon 1987
b. Frontal lobe dysfunction	Beauchet et al., 2002; Orrell et al., 1989
c. Learning disability	Williams et al., 1998
d. Personality disorder	Howard et al., 1993; Post et al., 1982; Robben 1991; Ungvari et al., 1991; Vostanis et al., 1992
e. Dementia	Klosterkötter et al., 1985; Orrell et al., 1991; Snowdon 1987; Wrigley et al., 1992
f. Schizophrenia	Klosterkötter et al., 1985; Snowdon 1987
g. Affective disorder	Klosterkötter et al., 1985; Snowdon 1987
h. Obsessive-compulsive disorder	Grignon et al., 1999
2. Mental Disorder of Old Age occurring along with self-neglect	
a. Paraphrenia/late onset schizophrenia	
b. Chronic depressive disorder	
c. Pathological grief	Klosterkötter et al 1985; Snowdon 1987
d. Capgras syndrome	Al-Adwani et al 2001
3. Medical conditions associated with Diogenes syndrome (Clark et al., 1975)	
Renal failure	Cerebrovascular disease, stroke
Malignancy	Parkinson's disease
Osteoarthritis	Cervical spondylosis
Leukaemia	Cardiac failure
Gangrene	Pulmonary embolism, bronchopneumonia

The variations in presentation have led to different classifications of this syndrome. A Dutch publication (Robben 1991) divided self-neglect in the elderly into two. The first related to homelessness and the second, Diogenes syndrome, i.e. those with homes but neglecting themselves and their environment. In 1957, a distinction was made between isolates and desolates (Townend 1957). There were other classifications by Howard et al. (1993) and Lowenthal (1964) using empirical research. The authors of that study divided patients into two, the pure isolates and the semi-isolates. Pure isolates not being characterized by psychiatric breakdown to a significant level.

Using factor analysis, Grignon et al. (1999) proposed 3 subtypes. They were a) the isolated lonely b) the non-isolated lonely c) the non-lonely isolates. The non-lonely isolates apparently had the temperament and the capacity to live alone. The same authors concluded that they often cause more suffering to others than themselves and hence any psychiatric opinion requested is because someone can no longer tolerate the disturbing situation.

Proposed causes and associated conditions

A third (Drummond et al. 1997) to 50% (Robben 1991) of patients with Diogenes syndrome do not have a comorbid psychiatric diagnosis, the other half to two-thirds have underlying psychiatric problems, mostly dementia (Wrigley et al. 1992). The former group has been hypothesised to have a late life coping crisis reflective of underlying personality problems (Post et al. 1982). Alternatively the syndrome has been described as more in keeping with frontal lobe dementia (Orrell et al. 1991). This view has been corroborated in another paper stating that there is an earlier age of onset for frontal lobe dementia (Gannon et al. 1992). Given that there is no single causative factor, a combination of factors is likely to be the most plausible cause.

In view of the expression of a hostile attitude and rejection of the community (Macmillan et al. 1966) it is important to keep in mind the various proposed psychological causes. Indirect self-destructive behaviour is a concept that has been around for a long time and neglecting self-care is considered (McIntosh et al. 1988) to be indirect self-destructive behaviour. So too is indirect life threatening behaviour (Thibault et al. 1999) keeping this in mind will help us understand them better.

There are various conditions that have been associated with Diogenes syndrome are given in Table 3.

Diogenes Syndrome: Its current clinical relevance

The behavioural phenotypes of Diogenes syndrome have been refined (Hanon et al. 2004) but have aroused many conflicting views (Drummond et al. 1997).

Litter hoarding, which according to some authors is an essential feature of Diogenes syndrome, has been described in many disorders across the board as cerebrovascular event (Ngeh 2000), Prader-Willi syndrome and dementia (Barocka et al. 2004).

The association of hoarding has been described with psychiatric disorders such as schizophrenia, ADHS or obsessive-compulsive disorders, delusional disorder and personality disorder (Barocka et al. 2004; Spear et al. 1997; Van Alphen

Table 2. Classification of self-neglect in the elderly

Author	Year	Proposed Classification
Townend	1957	A. Isolates
		B. Desolates
Lowenthal et al.	1964	A. Pure isolates
		B. Semi-isolates
Robben et al.	1991	A. Homelessness
		B. Diogenes Syndrome
Grignon et al.	1999	A. The isolated lonely
		B. The non-isolated lonely
		C. The non-lonely isolates

et al. 2005). It has also been described in a pair of siblings. (Post et al. 1982). Of the few papers on organic basis Diogenes syndrome, white matter changes in the brain have been implicated by one (Saiz Gonzalez et al. 2005).

Most likely Diogenes syndrome is a heterogeneous group of conditions, having varied and multi-modal causality. Many patients who are referred for assessment to a specialist psycho-geriatric unit would have self-neglect as a concern expressed by the GP. It is thus important to understand the possible mechanisms and pathways resulting in self-neglect, when evaluating these patients.

Management

There are no clear guidelines pharmacological or non-pharmacological on how best to manage people with Diogenes syndrome. There is a report of risperidone being effective (Herran et al. 1996) in this condition. This report highlights the response in an individual with no underlying psychosis. There are however no controlled trials or even case series in this area. Zolpidem has been used in a case with sleep disturbances (Kummer et al. 1995). The patients other symptoms required other forms of input. A recent article looks at paroxetine in compulsive hoarding and non compulsive hoarding concluded that it had a positive role in both groups (Sanjaya et al. 2007). There are others that have looked at the role of quetiapine and sodium valproate in managing patients with secondary bipolar disorder and Diogenes syndrome in front temporal dementia (Galvez et al. 2007). There are no reports on cholinesterase inhibitors specifically targeting Diogenes syndrome but there is literature to suggest a worsening of aggression and restlessness with frontotemporal dementia (Huey et al. 2006).

An article published in 1997 tried to address this issue (Jackson 1997). The initial emphasis is on establishing rapport, avoiding communication that leads to poor understanding of the issues, keeping the number of carers to a minimum, assessing over a period of time and treating deficiencies. The authors stress the lack of emergency (unless there is a medical or psychiatric issue that needs immediate attention) in a condition that has often evolved over years. However, they also state that the individual has a right to refuse help and that this should be respected while keeping in mind risk to the patient and neighbours.

The literature clearly states that these individuals come to the notice of mental health services when their conditions are no longer acceptable even if some may have been known to the services. Another set of authors have stated that day care and community support are the main lines of management advocated with a non intrusive, gentle, and persistent approach (Cooney et al. 1995).

A thorough assessment is very important and it is possible only to a certain extent while they are in the community. It is not advisable for people to put their health at stake while assessing the patients. The environment they live in is a risk to anyone let alone the patient. The initial contact however must be non-threatening, and respect for the individual needs to be kept in mind at times. Many of the people with

this diagnosis have led productive lives and have for some reason failed to maintain the standards they had earlier. Some may wish no contact out of shame (Isaacs et al. 1972). Gentle persuasion initially and finally use of the mental health act is probably the best approach as they are otherwise a risk to themselves and others.

Principles of treatment for self-neglect

If there are repeated failures in gaining access to the individual and if sufficient level of risk is perceived, use of the mental health act or National Assistance Act should not be delayed, the former being the preferred option.

Section 47 of the National Assistance Act is a useful tool but not used commonly (Wolfson et al., 1990) for the right reasons. The act is not patient-friendly and draconian. There is recommendation for its use (MacAnespie 1975), but a careful read through of the act will show how unfriendly an act it is. Once applied the patient has no automatic hearing, or access to one, unlike the mental health act 1983. Everything done has to be through the court.

A complete physical examination and blood screening is essential. This should include iron, folate, vitamins B12, C, D, calcium, serum proteins, albumin, and potassium. Liver function tests, renal function and thyroid status will serve as baseline tests.

Capacity and Ethics

The original mythology of Diogenes states that the simple life lived by Diogenes was a choice made by him. In the same vein it may be argued that medical intervention against patient's wish needs to be justified for individual patients. The patient needs to be assessed for risk to him and others. His capacity needs to be checked and only under very dire circumstances he may be detained under the Mental Health Act.

Outcome and Prognosis

Recent reports show lower mortality than the earlier reports. (Gannon et al. 1992; Roe 1977). A review by Spear et al. (1997) states that despite all efforts of cares the outcome and prognosis is usually poor. It goes on to state that there is 50% mortality after hospitalisation and that 25% are placed in long-term facilities. One study advises against the over-enthusiastic treatment of the frail elderly. It called hospital admission a refined form of cruelty (Baker 1976). Attendance in a day hospital has been shown to cause an improvement in patient's physical and psychological well being (Klosterkötter et al. 1985).

The outcome seems to depend on their ability to reintegrate with society, attendance at day centres and willingness to incorporate changes to their unhealthy living conditions. Early age of onset has a higher incidence of psychiatric morbidity (Snowdon 1987) and OCD with self-neglect has a

worse prognosis than OCD on its own (Drummond et al. 1997). Multiple physical problems/poor physical health predicts poor prognosis (Clark et al. 1976).

In a paper published fairly recently (Reyes-Ortiz 2001), the author highlights amongst the risk factors for Diogenes syndrome, having a stressful life event and sensory deprivation. The presence of a somatic illness and loneliness is also pointed out as a potential risk factor.

Genetic factors

The occurrence of obsessive compulsive disorder as a comorbidity lends to the possible heritability of the condition (Carol et al. 2007; Samuel et al. 2007). This is not a strong association and only a possible and tenuous one if one assumes that the condition is an obsessive compulsive spectrum disorder. There are no studies that have looked at Diogenes syndrome and heritability. There could be an association if one is to consider CADASIL as a possible underlying cause and the notch 3 gene involvement (Joutel et al. 1996).

Discussion

Assessing and managing self-neglect can be challenging for Geriatric Psychiatrists, Geriatricians and indeed the Social workers. There is lack of clarity and consensus as to the criteria for self-neglect and the existence of Diogenes syndrome as a distinct entity.

Assessing and managing these conditions require an understanding of the basic definition of what constitutes neglect. A recent paper looked at self-neglect as being part of a geriatric syndrome (Maria et al. 2006) due to the multifactorial aetiology, shared risk factors with other geriatric domains, association functional decline, and association with increased mortality. One can see the association but that does little to help with management. Cognitive dysfunction may be the trigger or the one of the consequences. Nutritional intake is poor and many have a very restricted intake, often limited to certain types of food.

While failure to conform to social norms (the society the individual lives in) should not be a criterion, there are certain requisites for adequate self care. There are unfortunately no specific cultural bias free guidelines. The depression years saw many people hoarding items in fear that if they ever needed it, it would be there. The recent years have been that of plenty. Whether we see a different picture to the overall pattern of self-neglect will be interesting to see and indeed should be studied. This only goes to show that even within races, there can be variations based on times of need and those of plenty.

It is important to differentiate between adequate and basic cleanliness. With the elderly population we are targeting basic cleanliness as the concept of adequacy will only lead on to more complications. Basic cleanliness will include a full

body wash at least twice a week, grooming that includes cutting nails, hair, shaving (daily for men), brushing teeth in the morning and a daily change of clothes. There are no clear recommendations but there are significant cultural variations.

In lay media, the reporting usually focuses on the filthy environment and hoarding behaviour. As to whether this is an integral part of Diogenes syndrome or not, one only has to look at the available literature to realise that even this 'typical' picture can be inconsistent. In their paper Clark et al. (1975) state that only some of their patients had hoarding as a feature. OCD occurring co morbid with Diogenes syndrome is one of the hypothesis put forward. It is as such important to look at this carefully and manage appropriately. There are however not many papers that have looked specifically at distinguishing between these features. And more research will certainly be needed.

Another contentious issue is individual rights versus the societal safety. For clinicians involved in the care of patients with self-neglect, it is easy to see the public health risk that can arise from the clutter and garbage but are left with little that they can rely on for direction. Family physicians are reluctant in UK to use the National Assistance Act as it is seen as being draconian, and quite rightly so. However, this brings in the question of the appropriateness of section 2 of the mental health act (for assessment). To assume that these individuals choose to live in this manner can be erroneous without a period of assessment in a safe environment. Social workers are however on occasions reluctant to support (this is the authors experience) the use of the mental health act. Reluctance to seek or accept help could be secondary to amotivation, depression, suspiciousness, paranoia, alcohol or other substance dependence rather than a desire to live in squalor. Aggression could also be the result of underlying personality traits becoming more pronounced secondary to dementia or intrusion of by 'well wishing' neighbours.

Studies in the past (Klosterkötter et al. 1985) found that as a group some of them had above average intelligence (25%). Even though the landmark study did formally test intelligence, they did not do so in all the patients'. There have since been cases of learning disability with Diogenes syndrome reported in literature (Williams et al. 1998).

'Lack of shame' is mentioned as one of the features (Cybulska et al. 1986), but does not have much acceptance by other reviewers. Whether this is lack of insight or shamelessness is not clear. Shame as a concept is more philosophical than clinical.

A foul odour that emanates from the house is one of the most consistent clinical features reported. If impaired olfaction is present, it could play a part in their squalor. However, more studies will be needed to ascertain the validity of this as a potential contributing factor. It is unlikely that these individuals actually flaunt their lack of cleanliness. The distinction is important if one were to take disorganised behaviour to be a component of psychosis. This would help us understand the response to risperidone (Herran et al. 1996).

The authors argue for the classification of self-neglect presentations into social, dissocial and asocial. Social self-neglecters are 'more integrated' or rather less marginalised or

isolated from society and 'appreciate' the input from family members. Such individuals when seen have regular input from family and look forward to family members visiting. Interventions should focus on involving the primary care givers and family practitioners in management plans.

Social services will be crucial in offering a clean up service and looking into risk of physical, emotional and financial abuse as well as financial planning. The occupational therapist can help assess issues around safety at home. However, it is important that the family is involved where appropriate in management plans. Tips on safety like asking for an ID card or calling before coming will go a long way in keeping patients safer in the community.

Encourage the patient to have a friend or family member to be present if they are comfortable with it. Regular mental state and cognitive assessments to identify early signs of memory loss are important. Cognitive strategies will also be helpful and has in the case of compulsive hoarders been found to be efficacious (Tolin et al. 2007; Saxena et al. 2004).

There seems to emerge groups based on certain features. Dissocial self-neglecters resent help but don't overtly object to it. Family members find it hard to help them due to their reluctance but manage to play a role in their lives occasionally. To involve the clean-up services is an option but will need the family members on board as apart of the planning team. Although it is possible that involvement of family members may be difficult due to reluctance on the patient's part to involve 'others'.

The asocial group actively object to it and are more likely to be admitted under the mental health act. They object and protest any kind of clean up service or help and are hard to engage in any way. When forced to go into hospital, there is grief for the loss of their independence and they may 'give up'. This group is most likely to have the worst outcome although there is a report of two patients of this group doing 'better' (Vostanis et al., 1992). There is no clear 'grief intervention' that has been tried for this sub group or indeed those with Diogenes syndrome in general in literature.

There may be a subgroup that 'litter and leave' as opposed to 'litter and live'. This, however, is not commonly reported. The authors have not seen such cases, but it is likely that they are not part of the typical spectrum of Diogenes syndrome as they seem to have insight and move to cleaner and healthier surroundings. Cultural factors should be taken into account.

The authors argue that given that there are many 'hues' to the severity of self-neglect, it warrants a dimensional approach. We could view self-neglect on a continuum, as a spectrum disorder with organic self-neglect on one extreme and pure Diogenes on the other. In between would be the co-morbidity with psychiatric conditions. This would help to include hoarding behaviour with self-neglect in the spectrum and help one to conceptualise the entity as one with a considerable overlap of symptoms. This approach is easier when dealing with such a condition offers much greater flexibility. And will be of qualitative research value. The authors strongly feel that there is a fairly urgent need to understand this sometimes very challenging group.

A change in terminology will not change the appropriateness of its use. What is important however is to use the term within the context of the presenting features so as to help the individual by tailoring the approach. This will certainly need more research, but an effective classification will go a long way in studying the different groups.

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