

Diogenes syndrome in patients suffering from dementia

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Diogenes syndrome (DS) is a behavioral disorder of the elderly. Symptoms include living in extreme squalor, a neglected physical state, and unhygienic conditions. This is accompanied by a self-imposed isolation, the refusal of external help, and a tendency to accumulate unusual objects. To explore the phenomenon of DS in dementia we searched for the terms: "Diogenes syndrome, self-neglect, dementia." It has long been understood that individuals with dementia often become shut-ins, living in squalor. In the Eastern Baltimore study, dementia was present in 15% of the elderly cases with moderate and severe social breakdown syndrome; twice as many as in the general population of the same age group. Researchers have underlined the frequent presence of DS (36%) in frontotemporal dementia (FTD): different neuropsychological modifications in FTD may contribute to symptoms of DS. The initial treatment should be a behavioral program, but there is not sufficient information regarding pharmacological treatment of the syndrome.

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Introduction

Diogenes syndrome (DS) is a behavioral disorder described in the clinical literature in elderly individuals: the classical constellation of symptoms of this condition include extreme neglected physical state, social isolation, domestic squalor, and tendency to hoard excessively (sylllogomania). Diogenes of Sinope was a 4th-century BC Greek minimalist philosopher, and one of the early cynics who advocated the principles of self-sufficiency and contentment unrelated to material possessions. He lived as he preached, sleeping rough in public buildings (some believe in a barrel) and begging for food, thus reducing his earthly needs to the barest minimum. His ideals were "life according to nature," "self-sufficiency," "freedom from emotion," "lack of shame," "outspokenness," and "contempt for social organization." The name of the syndrome is a reference to the reclusiveness and rejection of the outside world practiced by the philosopher but, according to Marcos et al, Diogenes would have never been diagnosed as having his "own" syndrome¹: 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. "High time to exonerate Diogenes of Sinope," pleads Cybulska, "Some names appear to stick to syndromes or diseases like proverbial glue, regardless of their total inappropriateness."² The eponym

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was first suggested in 1975 by Clark and collaborators, who described 30 geriatric patients with personalities characterized by suspiciousness, aloofness, hostility, and unfriendliness admitted to hospital in a state of severe self-neglect, and who were living in gross domestic squalor.³ It was, however, MacMillan and colleagues (1966) who conducted the first thorough investigation.⁴ They called the syndrome *senile breakdown*. It is also known as *self-neglect*,⁵ *senile squalor*,⁶ or *social withdrawal* in the elderly, and it has also been referred to in the German literature as *messy house syndrome*, and the victims, somewhat quaintly, as *messies*.⁷ In 1982, Post used the term *senile recluse* and argued that it is not a syndrome but merely an end stage of personality disorder.⁸ The syndrome has been defined as a “failure of social and personal care,”⁹ reflecting a public health point of view, rather than a psychiatric one. Acute, transient periods of social withdrawal and neglected self-care, such as in grief, are not included in the pure DS category; socially sanctioned patterns of withdrawal (monks, ascetics, etc), which are the result of a conscious decision based on ideological principles, are also not regarded as cases of DS.¹⁰ Little has been written about the forensic implications of this type of lifestyle and condition: the behavioral disorder reflects a significant functional problem contributing to increased morbidity and mortality.¹¹ Longitudinal studies clearly demonstrate that self-neglecting older adults have an independent increased risk of death after adjusting for a variety of predictors of mortality in this population, including comorbidity.¹² Miss Havisham from Dickens' *Great Expectations* might be a better example of the syndrome,¹³ but even more convincing descriptions can be found in Nikolaj Gogol's novel, *Dead Souls*.¹⁴

Epidemiology

The estimated annual incidence of DS is 0.5 per 1000 of the population aged 60 or over living at home,¹⁵ but DS may go unrecognized because it may mimic other behavioral or cognitive disorders.^{16,17} The age range in the Clark et al study is of 66 to 92 years (average, 79 years),³ although younger individuals have been described: 30.9% of cases in a selected sample was below 65 years of age.¹⁸ According to Shah and Reyes-Ortiz, the syndrome is not specific to a certain socioeconomic status or profession, and appears to be equally prevalent among men and women^{19,20}; on the other hand, there are

authors who consider the syndrome an entity which usually affects seniors living alone, more frequently women than men, and generally widows.^{3,21} While most reported cases have involved individuals who live alone, cases have been described in siblings and married couples, sometimes termed *Diogenes a deux*.^{22,23} Some authors reported women with children living in self-neglecting conditions, posing serious ethical dilemmas to the involved physicians.²⁴ The loss of a close relative who was caring for the patient appears to be the most important precipitating factor, initiating the deterioration in self-care in one third of cases.²⁵ Little is known about whether the disease concepts in DS derived from Western literature are applicable to non-Caucasian populations: Chan et al described the behavioral disorder in a case series of elderly patients in Hong Kong.²⁶

Nosographic aspects

The syndrome is not listed in current classifications of diseases such as *DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision)*,²⁷ *DSM-5 Draft Criteria*,²⁸ or *ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th edition)*,²⁹ since the features of this disorder are included in many diagnoses, but not as a specific disease. Medical and psychiatric comorbidities such as dementia, depression, obsessive-compulsive disorder, and alcoholism have been suggested as causes or contributors to the phenomenon. The behavioral presentation of DS is etiologically complex and psychiatric and/or neurological comorbidities may be, but are not necessarily, present. Reyes-Ortiz reviewed the literature on DS and introduced a distinction between primary and secondary DS, the latter being related to mental disorders ranging from paranoid schizophrenia to affective disorders.²⁰ This distinction reflects the observation that as many as 50% of Diogenes patients have no history of psychiatric illness.²⁰ Kummer et al described sleep-wake rhythm disorders in a patient with DS, but no other mental disorder.³⁰ Zolpidem and behavioral therapy improved sleep architecture, and partial reintegration of the patient was achieved. Relationship with obsessive-compulsive disorder and obsessive-compulsive personality disorder are observed,^{31,32} but, at present, available data are too scarce to draw any solid conclusions. DS has been reported in individuals with intellectual disability.³³ Donnelly et al presented a case report describing the

coexistence of DS and Capgras syndrome, a syndrome in which a patient believes that a person, usually close to the subject, has been replaced by an identical double.³⁴ A clinical form of frontal lobe dysfunction has been postulated to explain this syndrome,¹⁶ so executive dysfunction may have a role in the condition. It has also been suggested that DS may be a manifestation of a subclinical personality disorder—in particularly with schizoid and paranoid traits³⁵ unmasked by age.²⁰ It has been stated that many persons with DS commonly display subclinical personality traits including unfriendliness, stubbornness, aggressiveness, independence, eccentricity, paranoia, aloofness, detachedness, compulsivity, narcissism, and lack of insight.^{17,36-38} Some authors have questioned whether extreme self-neglecting behavior in old people is a form of indirect self-destructive, even suicidal, behavior.^{39,40}

Dementia and Diogenes

New-onset DS in older age may be due to dementia, for instance. Most patients showing self-neglect are diagnosed with dementia within 1 or 2 years of presentation.⁴¹ In fact, patients with dementia invariably develop progressive inability to take care of themselves. It has been long observed that individuals with dementia develop inability to assess critically what is of value, and that can result in the accumulation of trash and objects.⁴² In the Eastern Baltimore study, dementia was present in 15% of those with moderate and severe social breakdown syndrome, twice as many as in the general population of the same age group.⁴³ In the diagnostic consensus study of Neary et al, decline in personal hygiene is one of the supportive features of frontotemporal dementia (FTD).⁴⁴ Lebert underlines the frequent presence of DS (36%) in FTD⁴⁵: different neuropsychological modifications in FTD can contribute to symptoms of DS. Apathy, for example, can reduce the inclination to wash oneself and the alteration of executive functions can explain the simplification of complex tasks, such as maintenance of washing.⁴⁵ A possible link with frontal lobe dementia has been questioned due to the younger age of onset of this type of dementing disease.^{21,46} The prognosis is poor, with 5-year mortality rate of 46%, possibly due to physical complications.⁴⁷ Cognitive dysfunction may be the trigger or the one of the consequences, for example nutritional intake is poor and many have a very restricted intake, often limited to certain types of food.

A special problem is capacity, a term that, improperly, is often used interchangeably with competence. Competence is the quality or state of being functionally adequate or having sufficient knowledge, strength, and skill. Mental capacity is a functional term that may be defined as the mental (or cognitive) ability to understand the nature and effects of one's acts. Capacity may have several dimensions, including decisional ability, personal care, and self-care. There may be a variety of dimensions of capacity in which an older adult may be able to make some decisions but not others. Competence can fluctuate, according to some experts.⁴⁸ It is possible that individuals can retain some significant decision-making power even with advancing dementia, albeit usually not regarding health care. The diagnosis of dementia is not itself a criterion for incapacity.^{49,50} In addition, cultural considerations related to lifestyle and environmental patterns should be explored thoroughly during the capacity evaluation: forensic assessments can help to sort out dangerousness on the basis of dementia versus an eccentric lifestyle taken to the extreme.

Assessment and management

The assessment of DS must begin with gathering a comprehensive history, which should include a thorough history of behavioral disturbances. A complete physical examination and blood screening is essential: this should include iron, folate, vitamin B12, calcium, serum proteins, albumin, and potassium. Liver function tests, renal function, and thyroid status will serve as baseline tests. Neuroimaging studies are also necessary to rule out underlying medical causes. Such an evaluation would include neuropsychological and personality assessment along with consideration of the psychosocial factors which might be maintaining the self-neglect behavior. Management is a difficult issue: patients' continued refusal of help gives rise to complex ethical and medicolegal issues. Specifically, intervention usually does not occur at the request of the individuals themselves. The diversity of associated mental and physical health problems lends support to the argument that squalor may be treated best as a state associated with, or a consequence of, a range of physical and mental disorders which requires careful assessment and treatment, rather than as a rare syndrome due to reclusiveness or an eccentric personality.⁵¹ There are no clear guidelines, pharmacological or nonpharmacological, on how best to

manage people with DS, and there are no controlled trials or even case series in this area. However, management involves not only treatment of the underlying disease, but also an understanding of available service agencies. Day care and community care are the main lines of management rather than hospital admission. A safe environment should be provided, while respecting the patient's wishes as much as possible. Atypical antipsychotic agents have been used when paranoid symptoms are present. Herran and Vázquez-Barquero reported the case of a 77-year-old woman fulfilling criteria for dementia with symptoms of DS: treatment with risperidone improved the behavioral symptoms.⁵² Galvez-Andres et al described the significant improvements seen in FTD patients with DS after the start of treatment with quetiapine and sodium valproate.⁵³ The use of selective serotonin reuptake inhibitors to manage the compulsive hoarding behaviors has been reported.⁵⁴ Noncompliance with treatment and follow-up are common in patients with DS; thus the outcomes of the syndrome are poor despite efforts and care.⁵⁵ Gentle persuasion initially, and finally use of the mental health act is probably the best approach, as the patients are otherwise a risk to themselves and others.⁵⁶

Conclusion

Diogenes syndrome refers to a condition with distinct hoarding behaviors, severe self-neglect, and neglect in taking care of one's physical environment, as well as social isolation. It has been widely mentioned in the sci-

entific literature over the past 50 years, and poses complex clinical, social, and ethical challenges to the involved physicians. It does not correspond to a conscious decision, and should lead to a medical and social evaluation. The syndrome is etiologically complex, and psychiatric and/or neurological comorbidities may be present, but not necessarily so. Because the specific mechanism(s) of DS may not be readily apparent from a routine medical examination, a neuropsychological evaluation may be helpful in identifying the factors contributing to the dysfunctional behavior: careful differential diagnosis is critical to appropriate treatment selection, particularly with ever-increasing pharmacological options and to aid in the improvement of daily global functioning. Psychiatric disorders have been demonstrated in at least 50% of cases²¹; alternatively, it may be due to an exaggeration of a disorganized lifestyle or an indifference to personal care, both exacerbated by increasing age.³ Studies have confirmed the frequent presence of DS in FTD. Although dementia must be high on the list of differential diagnoses, there remains the possibility that the hoarding or cluttering behavior can be attributed to pre-existing personality traits. Physicians are obliged to treat DS, given the fact that it is a predominantly behavioral syndrome with clear risk to personal health and safety as well as the implications regarding environmental hazards (the foul odor that emanates from the house of the patients is a consistent clinical feature of the syndrome). □

The authors declare no conflict of interest.

REFERENCES

1. Marcos M, Gomez-Pellin MDC. A tale of a misnamed eponym. Diogenes syndrome. *Int J Geriatr Psychiatry*. 2008;23:990-991.
2. Cybulska E. Senile squalor: Plyushkin's not Diogenes' syndrome. *Psychiatr Bull R Coll Psychiatr*. 1998;22:319-320.
3. Clark AN, Mankikar GO, Gray I. Diogenes syndrome: a clinical study of gross neglect in old age. *Lancet*. 1975;1:366-368.
4. Macmillan D, Shaw P. Senile breakdown in standards of personal and environmental cleanliness. *BMJ*. 1966;2:1032-1037.
5. Reifler BV. Diogenes syndrome: of omelettes and souffles. *J Am Geriatr Soc*. 1996;44:1484-1485.
6. Shah AK. Senile squalour syndrome: what to expect and how to treat it. *Geriatr Med*. 1990;36:29-34.
7. Barocka A, Seehuber D, Schone D. Sammeln und Horten: ein Messie kann nicht anders. Die Wohnung als Mullhalde. [German] *MMW Fortschr Med*. 2004;146:36-39.
8. Post F. Functional disorders I. Description, incidence and recognition. In: Levy R, Post F, eds. *The Psychiatry of Late Life*. Oxford, UK: Blackwell; 1982:176-196.
9. Gruenberg EM, Brandon S, Kasius RV. Identifying cases of the social breakdown syndrome. In: Gruenberg EM, ed. *Evaluating the Effectiveness of Community Mental Health Services*. New York, NY: Milbank Memorial Fund; 1966:127-143.
10. Ungvari GS, Hantz PM. Social breakdown in the elderly. I. Case studies and management. *Compr Psychiatry*. 1991;32:440-444.
11. Byard RW, Tsokos M. Forensic issues in cases of Diogenes syndrome. *Am J Forensic Med Pathol*. 2007;28:177-181.
12. Lachs MS, Williams CS, O'Brien S, Pillemer KA, Charlson ME. The mortality of elder mistreatment. *JAMA*. 1998;280:428-432.
13. Dickens C. *Great Expectations*. London, UK: Chapman and Hall; 1861.
14. Gogol N. *Dead Souls*. London, UK: Penguin; 1961:120-128.
15. Berlyne N, Twomey J, Henderson Smith SL. Diogenes syndrome. *Lancet*. 1975;1:515.
16. Grignon S, Bassiri D, Bartoli JL, Calvet P. Association of Diogenes syndrome with a compulsive disorder. *Can J Psychiatry*. 1999;44:91-92.
17. Ngeh JK. Diogenes syndrome presenting with a stroke in an elderly, bereaved woman. *Int J Geriatr Psychiatry*. 2000;15:468-469.
18. Hurley M, Scallan E, Johnson H, de la Harpe D. Adult service refusers in the greater Dublin area. *Irish Med J*. 2000;93:208-211.

Síndrome de Diógenes en pacientes con demencia

El síndrome de Diógenes (SD) es un trastorno de la conducta de los ancianos. Los síntomas incluyen: vivir en la miseria extrema, un abandono del estado físico y condiciones antihigiénicas. Esto se acompaña de un aislamiento autoimpuesto, el rechazo a la ayuda externa y una tendencia a acumular objetos extraños. Para explorar el fenómeno del SD en la demencia se buscaron los términos: "síndrome de Diógenes, autoabandono, demencia". Desde hace tiempo se sabe que las personas con demencia con frecuencia llegan a estar confinados, viviendo en la miseria. En el estudio Eastern Baltimore la demencia se encontró en el 15% de los ancianos con un síndrome de desintegración social moderado o grave; el doble que en el mismo grupo etario de la población general. Los investigadores han destacado la presencia frecuente de SD (36%) en la demencia fronto-temporal (DFT) y diversas modificaciones neuropsicológicas de ésta pueden contribuir a los síntomas del SD. El tratamiento inicial debe ser un programa conductual, pero no hay suficiente información relacionada con el tratamiento farmacológico del síndrome.

Le syndrome de Diogène chez les patients souffrant de démence

Le syndrome de Diogène (SD) est un trouble comportemental des personnes âgées. Les symptômes consistent en des conditions d'hygiène déplorables, un aspect physique négligé et l'absence de soins corporels. Le tout accompagné d'un isolement auto-imposé, du refus d'aide externe et d'une tendance à accumuler des objets inhabituels. Pour explorer le phénomène du SD dans la démence, nous avons recherché les termes : « syndrome de Diogène, laisser-aller, démence ». On a longtemps cru que les individus déments ne sortaient plus de chez eux et vivaient dans des conditions d'hygiène déplorables. Dans l'étude de Baltimore Est, la démence était présente chez 15 % des personnes les plus âgées atteintes d'un syndrome de trouble social modéré à sévère ; deux fois plus que dans la population générale d'un même groupe d'âge. Des chercheurs ont souligné la présence fréquente de SD (36 %) dans la démence frontotemporale (DFT) : différentes modifications neuropsychologiques dans la DFT peuvent contribuer aux symptômes du SD. Le traitement initial devrait être un programme comportemental, mais les informations sur le traitement pharmacologique du syndrome ne sont pas suffisantes.

19. Shah A. Squalor syndrome: a viewpoint. *Aust J Ageing*. 1995;14:160-162.
20. Reyes-Ortiz CA. Diogenes syndrome: the self-neglect elderly. *Compr Ther*. 2001;27:117-121.
21. Cooney C, Hamid W. Review: Diogenes syndrome. *Age Ageing*. 1995;24:451-453.
22. Cole AJ, Gillett TP, Fairbairn AD. A case of self-neglect in a married couple: "Diogenes" à deux? *Int J Geriatr Psychiatry*. 1992;7:839-841.
23. Esposito D, Rouillon F, Limosin F. Diogenes syndrome in a pair of siblings. *Can J Psychiatry*. 2003;48:571-572.
24. O'Mahony D, Evans JG. Diogenes syndrome by proxy. *Br J Psychiatry*. 1994;164:705-706.
25. Ungvari GS, Hantz PM. Social breakdown in the elderly, II. Sociodemographic data and psychopathology. *Compr Psychiatry*. 1991;32:445-449.
26. Chan SM, Leung PY, Chiu FK. Late-onset Diogenes syndrome in Chinese—an elderly case series in Hong Kong. *Neuropsychiatr Dis Treat*. 2007;3:589-596.
27. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 4th ed. Text Revision. Washington, DC: American Psychiatric Association; 2000.
28. American Psychiatric Association. DSM-5 Development Website. Available at: www.dsm5.org/Pages/Default.aspx. Accessed October 11, 2012.
29. World Health Organization. *ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines*. Geneva, Switzerland: WHO; 1992.
30. Kummer J, Gundel L. Sleep-wake rhythm disorders in the framework of a Diogenes syndrome. Improvement in sleep architecture using supportive treatment with zolpidem. *Fortschr Med*. 1995;113:149-150.
31. Drummond LM, Turner J, Reid S. Diogenes' syndrome—a load of old rubbish? *Ir J Psych Med*. 1997;14:99-102.
32. Seedat S, Stein DJ. Hoarding in obsessive-compulsive disorder and related disorders: a preliminary report of 15 cases. *Psychiatry Clin Neurosci*. 2002;56:17-23.
33. Williams H, Clarke R, Fashola Y, Holt G. Diogenes' syndrome in patients with intellectual disability: "a rose by any other name." *J Intellect Disabil Res*. 1998;42:316-320.
34. Donnelly R, Bolouri MS, Prashad SJ, Coverdale JH, Hays JR, Kahn DA. Comorbid Diogenes and Capgras syndromes. *J Psychiatr Pract*. 2008;14:312-317.
35. Vostanis P, Dean C. Self-neglect in adult life. *Br J Psychiatry*. 1992;161:265-267.
36. Salmon E, Degueudre C, Franco G, Franck G. Frontal lobe dementia presenting as personality disorder. *Acta Neurol Belg*. 1996;96:130-134.
37. O'Shea B, Falvey J. Diogenes' syndrome: review and case history. *Ir J Psych Med*. 1997;14:115-116.
38. Jackson GA. Diogenes syndrome—how should we manage it? *J Ment Health*. 1997;6:113-117.
39. Thibault J, O'Brien J, Turner L. Indirect life-threatening behaviour in elderly patients. *J Elder Abuse Neglect*. 1999;11:21-32.
40. McIntosh J, Hubbard R. Indirect self-destructive behavior among the elderly: a review with case examples. *J Gerontol Social Work*. 1988;13:37-46.
41. MacKnight C. Taking the solitude out of self-neglect in the elderly. *Can Alzheimer Dis Rev*. 2001;July:18-21.
42. Weiss KJ. Hoarding, hermitage, and the law: why we love the Collyer brothers. *J Am Acad Psychiatry Law*. 2010;38:251-257.
43. Radebaugh TS, Hooper FJ, Gruenberg EM. The social breakdown syndrome in the elderly population living in the community: The Helping Study. *Br J Psychiatry*. 1987;151:341-346.

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44. Neary D, Snowden JS, Gustafson L, et al. Frontotemporal lobar degeneration: a consensus on clinical diagnostic criteria. *Neurology*. 1998;51:1546-1554.
45. Lebert F. Diogene syndrome, a clinical presentation of fronto-temporal dementia or not? *Int J Geriatr Psychiatry*. 2005;20:1203-1204.
46. Gannon M, O'Boyle J. Diogenes syndrome. *Ir Med J*. 1992;85:124.
47. Hanon C, Pinquier C, Gaddour N, Saïd S, Mathis D, Pellerin J. Diogenes syndrome: a transnosographic approach. *Encephale*. 2004;30:315-322.
48. Mauk KL. Ethical perspectives on self-neglect among older adults. *Rehabil Nurs*. 2011;36:60-65.
49. Defanti CA, Tiezzi A, Gasparini M, et al; Bioethics and Palliative Care in Neurology Study Group of the Italian Society of Neurology. Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioral disorders. *Neurol Sci*. 2007;28:216-231.
50. Gevers S. Dementia and the law. *Eur J Health Law*. 2006;13:209-217.
51. Halliday G, Banerjee S, Philpot M, Macdonald A. Community study of people who live in squalor. *Lancet*. 2000;355:882-886.
52. Herran A, Vazquez-Barquero JL. Treatment of Diogenes syndrome with risperidone. *Aging Neuropsychol Cogn*. 1999;6:96-98.
53. Gálvez-Andres A, Blasco-Fontecilla H, González-Parra S, Molina JD, Padín JM, Rodríguez RH. Secondary bipolar disorder and Diogenes syndrome in frontotemporal dementia: behavioral improvement with quetiapine and sodium valproate. *J Clin Psychopharmacol*. 2007;27:722-723.
54. Saxena S, Maidment KM. Treatment of compulsive hoarding. *J Clin Psychol*. 2004;60:1143-1154.
55. Badr A, Hossain A, Iqbal J. Diogenes syndrome: when self-neglect is nearly life threatening. *Clin Geriatr*. 2005;13:10-13.
56. Amanullah S, Oomman SK, Shankar Datta SS. "Diogenes syndrome" revisited. Available at: <http://www.gjpsy.uni-goettingen.de/gjp-article-amanullah.pdf>. Accessed October 11, 2012.