

Late-onset Diogenes syndrome in Chinese – an elderly case series in Hong Kong

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Abstract: We review a consecutive case series of elders presenting to a regional psychogeriatric service in Hong Kong in 1996–2001. Eighteen elders (aged 65 and over) fulfilled the classical symptoms of Diogenes syndrome (extreme squalor, neglected physical state, unhygienic condition & social isolation with or without hoarding). A diverse clinical and socio-demographic profile was observed. Most of our clients suffered from different stages of dementia. Other diagnoses such as schizophrenia and alcohol abuse were diagnosed in this cohort as co-morbid or independent conditions. Neither psychopathology nor social situations could adequately account for the initiation and perpetuation of Diogenes syndrome in some cases. The plausible psychological etiologies are discussed in the context of existential values in Chinese culture and changes in traditional family dynamics as the society modernizes.

Keywords: Diogenes syndrome, senile squalor, social breakdown, hoarding, Chinese culture.

Introduction

Diogenes syndrome (DS) is named after the Greek Philosopher “Diogene de Sinope”, who taught cynicism philosophy. This is a well-known but relatively rare condition in daily clinical practice. The classical constellation of symptoms includes extreme squalor, a neglected physical state, unhygienic conditions and social isolation with or without hoarding (MacMillan and Shaw 1966; Clark et al 1975). There is a dearth of epidemiologic data on the prevalence and risk factors associated with Diogenes syndrome because of its low base rate of occurrence. The relatively limited literature on sporadic cases and case series from Caucasian populations published since 1960s purport to diverse clinical correlates that are largely related to cognitive impairment due to various neuropsychiatric disorders. In some case series, at least half of the cases had psychiatric disorders with the commonest diagnosis being dementia, followed by alcohol abuse, affective disorders and paraphrenia (MacMillan and Shaw 1966; Clark et al 1975; Snowdon 1987; Wrigley et al 1992; Halliday et al 2000). One third of the 29 cases in the Irish Series had no psychiatric diagnosis (Wrigley et al 1992). Subtle frontal lobe dysfunction was reported in some cases of DS not fulfilling diagnostic criteria of dementia (Orrell et al 1989). The personality profile of cases was often described as aloof, suspicious, detached, aggressive (Clark et al 1975), compulsive and narcissistic (Drummond et al 1997; Jackson 1997; O’Shea 1997; William et al 1998; Ngeh 2000). Little is known if these disease concepts on Diogenes syndrome derived from Western literatures are applicable to non-Caucasian populations. While hoarding is a common symptom of DS (though not necessarily the core symptom), there is a separate body of literatures on hoarding behavior, which is often associated with obsessive compulsive disorder in some series (Rasmussen and Eisen 1989; Frost and Gross 1993; Frost et al 1996). There was one paper reporting a case series of thirty community-dwelling Chinese adults with severe and long-standing hoarding behavior in Hong Kong (Chiu et al 2003). Eighty percent of cases in this series suffered from psychiatric disorders, comprising

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schizophrenia in more than half of the cases. None of the clients in this series were remarked to have significant self-neglect. To date, little is known about the clinical presentation of DS in Chinese communities.

Hong Kong is one of the most developed cities of China that situates at the confluence of Chinese and Western cultures. It is a small city of 1,078 kilometer square that hosts a huge population of 6.94 million (as of mid-2005). As a former British Colony and now a Special Administrative Region of People's Republic of China, Hong Kong has witnessed a number of major socio-economic-political transitions over the past century. Specialized health services and social policies for elders only started to catch up in 1990s in face of a rapidly ageing population. The Psychogeriatric Team of The Chinese University of Hong Kong (CUHK-PGT) was established since 1994 as one of the five regional services for elders in the public health sector. It provides multidisciplinary outpatient, inpatient, consultation-liaison and assertive outreaching services accessible and affordable to an elderly population of 750,000 in the New Territories East Districts. Standard pathways to care include (i) direct referral by primary care physicians in the public sector or private sector; (ii) direct referral (or via consultation-liaison service of PGT) by tertiary care doctors from other specialties; (iii) referral by social workers or caregivers via the Old-age community mental health service teams. Mental health service in HK partners closely with the government's social welfare sector in care-planning. The government also heavily subsidizes the health care expenditure of elders with financial difficulties. The extensive network of non-government organizations also provides day-care, short-term respite and care-giver support services to the community and these programs are funded by the government. The psychogeriatric service is complemented by geriatric medical service that takes care of dementia patients without behavioral or psychiatric symptoms. Of the 4000 clients presenting to the CUHK PGT in 1996–2001, 18 elders fulfilling the general descriptions of Diogenes syndrome were identified. Since 80%–90% of elders rely on the health care provision by the public health sector, this case series is presumably representative of elders living in squalor in the community served by the CUHK-PGT. This paper aims at systematically addressing the social situation, pathway to care and psychopathological profile surrounding the development of Diogenes Syndrome in the context of Chinese culture and a modernized society. A brief overview of the social and clinical profile of this cohort is shown in Table 1. In this paper, all subjects are anonymous and they are identified as Case 1–18 in Table 1.

Clinical and socio-demographic profile

Socio-demographic profile

All elders were Chinese who spoke local Cantonese dialect. All of them have been living in Hong Kong since early adulthood. The eleven female patients were aged 68–91 years at first presentation (mean age = 76.5 years). 8 out of 11 were widowed, one never married and the remaining two were married. All female patients had never received any formal education with exceptions to the two patients (Case 5 and Case 8) who received 9 and 4 years of education respectively. The seven male patients were 68–89 years old at first presentation (mean age = 76 years). 4 out of 7 were never married and three were married. The male patients were better educated than the female cases on average. Two male patients were exceptionally well educated. For instance, Case 18 was a university graduate and Case 14 completed secondary school. Four male patients studied up to primary school level and one had never received any education. Case 3 and Case 14 were a married couple living in the same household.

Living condition and social support

16 patients lived in small apartments (around 20–30 square meter) in multi-storey buildings managed by the Government's Housing Department. A 77-year-old widowed woman (Case 1) lived in squatter house and a 72-year-old single man (Case 12) lived in a private elderly hostel. There were 7 patients who lived alone. The remaining 11 patients were either living with their spouses or elderly roommates. All of them had little contacts with their first-degree relatives. Even the married ones with children were virtually not in contact with their children. None of them endorsed any meaningful social support with friends, religious bodies or health-care professionals. Except for Case 5 (a 78 year-old reasonably well-educated widow) who subsisted on personal savings, the other elders were dependent on social security.

Behavioral symptoms of DS

At their first presentations, all 18 elders were in states of extreme squalor. Almost half of them had electrolyte disturbances, malnutrition, anemia or exacerbated pre-existing medical illness. Excessive hoarding of garbage including rotten stuffs and other futile objects occurred in all but 3 elders (Cases 2, 4, and 8). The three elders who did not exhibit hoarding behavior had remarkably poor

Table 1 The socio-demographic and clinical profile of the 18 cases of Diogenes syndrome presenting to the psychogeriatric team of the Chinese university of Hong Kong (CUHK PGT) in 1996–2001

Case no	Date of referral/years of "untreated" DS	Age/Gender/marital status	Educational level/Best premorbid occupational level	Living condition/Source of income	Self-neglect	Hoarding	Axis I/II psychiatric diagnosis or non-cognitive mental-behavioral Sx	Dementia syndromes
1	1996/unknown	77 yrs/Female/Widowed	No formal education/Housemaid	Living alone in squatter house/Social security	Yes	Yes	Visual hallucination	Mild cognitive impairment
2	1997/3 yrs	89 yrs/Male/Married	Primary level/Laborer	Living with wife in government apartment/Social security	Yes	No	Grandiose delusion	Alzheimer's dementia, moderate
3	1997/1 yr	71 yrs/Female/Married	No formal education/Housemaid	Living with husband in government apartment/Social security	Yes	Yes	Nil	Alzheimer's dementia, severe
4	1998/1 yr	73 yrs/Male/Single	Primary level/Construction worker	Shared apartment with a friend in government housing/Social security	Yes	No	Nil	Vascular dementia moderate
5	1998/1 yr	78 yrs/Female/Widowed	Nursing school/Midwife	Shared apartment with a friend in government housing/Personal savings	Yes	Yes	Persecutory delusion against her son	Alzheimer's dementia, mild
6	1998/3 yrs	83 yrs/Female/Widowed	No formal education/Housemaid	Living alone in government apartment/Social security	Yes	Yes	Nil	Alzheimer's dementia, moderate
7	1999/2 yrs	73 yrs/Female/Single	No formal education/Housemaid	Living alone in government apartment/Social security	Yes	Yes	Nil	Alzheimer's dementia, moderate
8	2000/2 yrs	79 yrs/Female/Widowed	4 years/Housemaid	Living alone in government apartment/Social security	Yes	No	Nil	Alzheimer's dementia

(Continued)

Table 1 (Continued)

Case no	Date of referral/ years of "untreated" DS	Age/Gender/ marital status	Educational level/ Best premorbid occupational level	Living condition/ Source of income	Self-neglect	Hoarding	Axis I/III psychiatric diagnosis or non-cognitive mental-behavioral Sx	Dementia syndromes
9	2000/2 yrs	74 yrs/Female/ Widowed	No formal education/ Housemaid	Living alone in government apartment/Social security	Yes	Yes	Alcohol dependency syndrome	Dementia, severe
10	2000/2 yrs	91 yrs/Female/ Widowed	No formal education/ Factory worker	Living alone in government apartment/social security	Yes	Yes	Nil	Alzheimer's dementia, mild
11	2001/10 yrs	75 yrs/Female/ Widowed	No formal education/ Hawker	Shared apartment with a friend in government housing/Social security	Yes	Yes	Set fire on garbage	Nil
12	2000/1 yr	72 yrs/Male/Single	No formal education/Laborer	Private old-age home/Social security	Yes	Yes	Mental deficiency (WAIS-IQ= 63)	Vascular dementia, moderate
13	2000/2 yrs	72 yrs/Male/ Married/	Primary level/ Civil servant (Workman)	Living with wife in a government apartment/ pensioner	Yes	Yes	Alcohol dependency syndrome; Antisocial personality disorder	Alzheimer's dementia, moderate
14	1997/1 yr	83 yrs/Male/ Married	Secondary level/ Bank teller	Living with wife in government apartment/Social security	Yes	Yes	Nil	Mild cognitive impairment
15	2000/10 yrs	68 yrs/Female/ Married	No formal education/Laborer	Living with husband in government apartment/Social security	Yes	Yes	Paranoid schizophrenia (onset >40 yrs ago)	Nil
16	2000/unknown	72 yrs/Female/ Widowed	No formal education/ Cinema attendant	Shared apartment with a friend in government housing/Social security	Yes	Yes	Nil	Nil

Table 1 (Continued)

Case no	Date of referral/ years of "untreated" DS	Age/Gender/ marital status	Educational level/ Best premorbid occupational level	Living condition/ Source of income	Self-neglect	Hoarding	Axis I/III psychiatric diagnosis or non-cognitive mental-behavioral Sx	Dementia syndromes
17	2001/3 yrs	68 yrs/Male/Single	Primary level/ Waiter	Shared apartment with a friend in government housing/Social security	Yes	Yes	Alcohol dependency syndrome	Nil
18	2001/1 yr	73 yrs/Male/Single	University/ Architect assistant	Living alone in government apartment/Social security	Yes	Yes	Nil	Nil

skin condition (eczema and secondary infection) and hair hygiene. Their apartments were also odorous (fecal smell) with infestation.

Cognitive symptoms

All patients were assessed for dementia syndromes using the DSM-IV Diagnostic Criteria (American Psychiatric Association 2000), NINCDS-ADRDA (McKhann et al 1984) and NINDS-AIREN (Roman et al 1993). Dementia syndromes were staged according to the Clinical Dementia Rating Scale (Hughes et al 1982).

Among the 11 female patients, one patient (Case 9) suffered from alcoholic dependency syndrome with comorbid dementia in severe stage and six patients had varying stages of Alzheimer's dementia. One female patient (Case 1) was diagnosed Alzheimer's dementia two years after first presentation. Another female patient (Case 11) was retrospectively confirmed to have mild-grade mental retardation. No evidence of dementia was found in the remaining two female cases.

At first presentation, 2 male patients (Case 2 and Case 13) had Alzheimer's dementia and another two male patients (Case 4 and Case 12) had Vascular Dementia. One male patient (Case 14) who did not meet criteria for dementia at first presentation, deteriorated cognitively in the subsequent two years with concurrent finding of infarct on CT brain and was subsequently diagnosed to have vascular dementia.

Other axis I psychopathology and personality traits

Multi-axial psychiatric assessment was performed on all subjects using the DSM-IV Criteria. Perceptual disturbance and/ or persecutory delusion was observed in 2 female patients who were demented at presentation (Cases 1 and 5). Another demented female case (Case 9) had history of alcohol dependency syndrome for 20 years but had stopped drinking for a year before she was first known to our service. Two patients (Case 15 and Case 11) set fire on garbage at home and they had Paranoid Schizophrenia and mental retardation respectively. Two male patients had alcohol dependency syndrome (Cases 12 and 17), either occurring alone or in association with dementia. Case 12 had anti-social personality disorder with repeated criminal convictions in adulthood. He also threatened violence to a hostel co-tenant with sharp weapons when he was presented to our service. Case 2, an 89-year-old man, had grandiose delusion on top of dementia while Case 13, a married 72-year-old

man living with wife had morbid jealousy, persecutory delusion and violent gesticulation at first presentation. None of the cases in this cohort had lifetime or current diagnoses of mood disorder or obsessive-compulsive disorder.

Pre-morbid occupational functioning

All female patients in this cohort had been able to sustain gainful employment in their adulthood. Most worked as semi-skilled or unskilled workers (such as housemaid, hawker, usher in cinema, and manual laborer). One exceptional case (Case 5) worked as registered nurse and midwife until retirement. The job profile of male cases included mostly manual laborers, government workman, construction site-worker or driver before retirement. There was one who studied to grade 7 and had worked as bank-teller until retirement (Case 14). The only university graduate (Case 18) in this cohort had worked shortly as assistant in Architect Firm and he had been financially dependent on his family and later Government's Social Security Scheme.

Referral pathway

None of the cases were self-referred. It was often the neighbors from other households who made complaints to local housing management office for bad odors and infestations resulted from our clients' self-neglect, squalor and hoarding. A few cases were brought to social workers' attention during routine social welfare enquiries. All patients, except Case 18, were eventually known to the Family Service Center of the Government where social workers made urgent referral to our Psychogeriatric Team. Outreach services were often needed for the initial assessments. The durations of "untreated" state of squalor ranged from 1–3 years in most male and female patients. Interestingly, Case 11 and Case 15 were not known to our service until 10 years from onset. They were living with their spouse/partner who did not manifest symptoms of self-neglect. The "non-case" spouses were not mentally ill otherwise. They were not the referrer and they, for unknown reasons, adopted avoidant and non-interfering attitude to the squalid state of the patients. Case 12 lived in a single-room of a private elderly hostel that offered low level of supervision to clients. He refused bathing and hoarded a lot of futile stuffs in his room. He displayed violent gesture when persuaded to clean up. The hostel staff tolerated his behavior for 8 months until he threatened violence to a co-tenant.

Clinical management and outcomes as of last follow-up in 2006

Initial management

Most patients were managed as outpatients with enhanced care from para-medical professionals and social workers. Three patients (Cases 2, 4, and 13) needed a short period of compulsory psychiatric inpatient treatment for their psychotic symptoms, violent gesture or disturbing behavior.

Subsequent follow-up

Two male patients with dementia (Cases 2 and 13) died from medical illnesses in the year after first presentation. Three female patients were lost to psychiatric follow-up for various reasons within a year from first presentation- for instance, Cases 3 and 6, both dementia patients, returned to Mainland China to join their relatives; Case 15, with history of Paranoid Schizophrenia, moved to another district and was lost to psychiatric follow-up after the first ever inpatient psychiatric treatment.

With enhanced care from home-helpers, social workers and community psychiatric nurses, two female patients (Case 14 and 16) and one male patient (Case 18) could be maintained in the community with some improvement in physical state and environmental hygiene. These three patients who could sustain in the community were all void of significant cognitive impairment or other psychiatric symptoms. The remaining 10 patients (6 female and 4 male) were eventually admitted to high-dependency nursing homes within two years from first presentation because of cognitive decline.

Discussions

The psychopathological profile (cognitive impairment, psychosis, substance abuse, personality problems), resistance to service engagement and lack of adequate response to treatment observed in our case series are compatible with those from other socio-cultural settings. Surprisingly, we did not find Major Depression in our case series as reported in some case series from Caucasian populations. The state of squalor was also not better accounted for by poverty as the coverage of social welfare scheme in Hong Kong provides a safety net for all local elders to guarantee a reasonable and safe standard of living in terms of shelter, clothing, food, transport and access to health care.

Based on the high prevalence of cognitive disorder (in the context of dementia, "dementia precox" of schizophrenia) in most case series of DS, it is reasonable to conceptualize

the evolution of DS as follows: cognitive dysfunction leads to self-neglect by way of forgetfulness, poor insight and judgment; perseverative component of cognitive impairment fuels hoarding behaviors; marginalized social support sustains states of squalor; and cognitive rigidity (in the context of dementia, chronic severe mental disorder or personality problems) adds to social breakdown that in turn increases resistance to service engagement. Along this pathway, there is a rate-limiting step of “initiation of self-neglect” and the other psychosocial elements of Diogenes Syndrome are merely perpetuation of the initiated state of self-neglect.

However, the speculated “pathogenesis” often fails to apply to cases without apparent Axis I/II psychopathology or cognitive impairment. One may argue that these cases without diagnosable psychiatric disorders merely reflect several possibilities, (1) the categorical approach adopted in conventional diagnostic criteria is insensitive to dimensional psychopathology, including subtle impairment in Executive Cognitive Function; (2) these cases have prodromal psychiatric disorders or cognitive disorders; (3) there is lack of valid personality assessment since knowledgeable informants are often unavailable. In our case series, however, none of the patients who did not fulfill diagnostic criteria for dementia and other psychiatric disorder (Cases 16–18) had significant cognitive decline or evolution of other psychopathologies as of their latest psychiatric assessments in 2006. In the absence of psychiatric disorder, the unique social situation in Hong Kong makes the development of DS in our socio-cultural context even more difficult to comprehend, compared to case series from western countries with lower population density. Intuitively speaking, the crowded living condition in Hong Kong should serve as a powerful deterrent to the development of DS. What might have possibly overcome this deterrent factor? We would like to consider this from a cultural-ethnographic perspective.

The process of modernization and globalization has shaken the age-old traditional Chinese existential value that has always been deeply rooted in family. “Family” validates an individual’s core existential values. Traditional Chinese families tend to be collectivistic and enmeshed. Trans-generational family members often live in the same household in the old days. At the same time, inter-familial boundaries are over-emphasized and most people adhere to the social convention that one should not intrude on other families. In the process of industrialization and modernization, new generations separate from their predecessors. The trans-generational chiasm widens both psychologically and geographically. For some maladjusted

trans-generational families that fail to re-link effectively across generations, the remnant family members from the older generation become very dysfunctional without alternative social support system. Against this background, these marginalized elders become entrapped in their empty nests and they are stripped of their core existential values. In psychological terms, these could amount to, even in the absence of other Axis I or Axis II psychiatric disorder, state of demoralization (Kissance 2001)- a prominent form of existential distress in which meaninglessness, hopelessness and helplessness predominate and yet this can be differentiated from depression by their mood reactivity and biological symptoms. This cultural-ethnographic axis might explain in part the initiation of DS in cases without Axis I & II psychiatric disorder; and the over-emphasis on inter-familial boundaries in Chinese culture perpetuate the isolation and marginalization of these at-risk elders, irrespective of the underlying socio- and psycho-pathology.

While the key etiological factor for the initiation and perpetuation of DS in most of our cases is apparently psychopathology, the fact that more than half of the cases were living with someone in small apartments at the time of presentation renders this explanation unsatisfactory. What makes the person who shares the household with the DS patient endure the unhygienic situation without calling for help? From the available clinical information, these “co-tenants” in our series were also socially isolated. They could well be marginalized and entrapped in the modern society and became demoralized themselves, which in turn delayed their help-seeking.

Conclusion

While psychiatrists are aware of the fact that DS is an ill-defined diagnostic entity in psychiatry, we are obliged to “treat” Diogenes syndrome given its being a predominantly behavioral syndrome with clear risk to personal health and safety as well as the implications on environmental hazards. DS, in a nutshell, comprises of a façade of eccentricity, underlying social adversities and/or psychopathology – the latter component often does not lend itself as a robust logical explanation to its eccentric facade. Psychological explanations in a cultural context seem to be an important component in the etiological model of DS. Although it is clear that clients presenting with DS are not motivated by a philosophical desire as the syndrome’s name suggests (Cooney et al 1995), as clinicians we might as well be conscious that we are not just facing a medical problem but a philosophical notion – the existential issues of individuals

as traditional cultural values fall apart in the course of modernization and globalization.

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