THROUGH THE LOOKING GLASS

Diogenes Syndrome or Syndrome of extreme self-neglect
The tragedy of a 85-year-old rubbish picker dying amidst her rubbish

A 85-year-old woman was hospitalized via an accident and emergency department for limb weakness, reduced appetite, sense of fear and anxiety. She used to live with two other elderly people in a home for senior citizens, but the two roommates have been hospitalized, leaving her alone. It was recorded that she expressed fear of death and loneliness, had reduced appetite and was depressed. She had no past medical illness, was an ex-smoker and not an alcoholic. No physical abnormalities were detected. Electrocardiogram revealed evidence of old inferior myocardial infarction and chest radiography showed changes of old tuberculosis. No blood tests or further investigations were ordered. She was referred to a medico-social worker. On the fourth day, she was noted to be calm and was discharged home. However, she was brought to the accident and emergency department of another hospital in the next morning, and was certified dead on arrival. Autopsy was not revealing as the coroner’s inquest was only concerned with whether she died of natural or unnatural cause.

A “psychosocial post-mortem” based on the information gathered by press reporters was more illuminating into her illness. This 85-year-old woman had been living alone in an estate for over ten years. Her son, who had emigrated early, occasionally mailed her some money to support her living. She used to be talkative and was in good contact with neighbours till half a year ago, when she had personality change - frequently sitting alone in the corridor, looking unhappy, and starting to collect rubbish. Her 200 square feet home was packed with empty cans, waste paper, magazines, and other rubbish, piling up to a height exceeding that of a person (Figure 1). Its entrance was also blocked by rubbish, leaving behind a small gap for her to squeeze through. Because of the foul smelling rubbish and the frequent haunts by rats, her neighbours had complained to the Housing Department. However, some neighbours did sympathize her. Knowing that this old woman had frequent falls, they kept a watchful eye on her. Five days before her death, her neighbours noted that she had not been out for days, and phoned up her younger sister, who hurried in and found that she had not been taking food for quite a number of days and her lower limbs were weak. She was thus brought to a hospital. She was discharged home in the morning(at 11 a.m.) on the fourth day. However, her home was so packed with rubbish that she had difficulty in getting entry, and she wandered near her home. Fearing that she might be in danger, her neighbours called the police for help. The police instructed her to remove some rubbish from her home but she refused. Twelve hours later (at 11 p.m.), one neighbour noticed that the door of her home remained open, and she was sitting on the floor with one foot seemingly trapped by the door. Her neighbour offered help, but she declined. At 7am the next morning, her neighbour found that she was lying unconscious by the door, which was blocked by rubbish and could not be opened. Police was called, and, on breaking in, she was found lying still with one foot trapped by the door. She was ambulanced to a hospital but she died on arrival. It was thought that when the old woman attempted to squeeze through the door into her home in the evening, the heaps of rubbish behind the door suddenly collapsed onto the door and trapped her trailing foot. It was reported that, being weak and old, she might have been trapped by the door for eight hours and died. The police subsequently discovered that, among the heaps of rubbish in her home, there were notes amounting to HK$9000 and her “Return-to-China Certificate”, which were believed to be the most valuable belonging inside her home.

This old woman fits into the description of Diogenes Syndrome\(^1\), also known as senile breakdown\(^2\), social breakdown in the elderly \(^3\), senile squalor \(^4\), or syndrome of extreme self-neglect \(^5\). The syndrome is characterized...
by social withdrawal, self-induced abysmal living conditions, refusal of help, and a tendency to hoard rubbish (syllogomania)\(^5,6\). The reported cases show heterogeneity \(^5\) in terms of cognitive status, psychiatric condition, socioeconomic status, and medical comorbidity. It affects all socioeconomic groups and includes a wide range of psychiatric and medical conditions: dementia, manic-depression, schizophrenia, paraphrenia, congestive heart failure, stroke, bronchopneumonia, malignancy, and Parkinson's disease. Up to half have no psychiatric disorders\(^5,6\). The pathogenesis is postulated to be an interaction between a vulnerable personality (detached, stubborn, eccentric traits) and stressful medical or social life events (e.g. bereavement, debilitating physical problems), resulting in gross self-neglect and social retreat\(^1,2,3,5,6\). It may lead to malnutrition and anaemia, and patients tend to present in crisis. Despite practical difficulties in management, the condition is potentially treatable\(^5\). Successes have been reported with drug management and behavioral reinforcement\(^7\), and attendance at day centre \(^2\). A proactive and coordinated outreach community care (e.g. meals-on-wheels)\(^5,6\) is preferable to hospital admission or nursing home placement.

The diagnosis of Diogenes syndrome in this 85-year-old woman was retrospective, and was based on the information gathered by the press reporter after her death. She might have an underlying debilitating physical illness resulting in reduced appetite, progressive immobility, instability, frequent falls and ultimately a home-bound state. A precarious social support network left this singleton starved and dehydrated for a number of days before she was finally brought to a hospital. Unfortunately she was thought to have a social problem only. When discharged back home, she was too frail to struggle through a door blocked by rubbish and the tragedy occurred. The press commented that "the rubbish she had accumulated for half a year killed her" as if she had dug her own grave. The cause of this tragedy is, however, multifactorial: a complex interaction of medical and psychosocial factors: isolation, poverty, instability, immobility, dehydration, subnutrition, depression, frailty. The "trap by the door" is only the last straw that breaks the camel's back. Fox \(^8\) had rightly pointed out the fallacy of the prejudicial label "social problem", which plays down what might actually be a social crisis with a pseudo-silent or missed presentation: problems that need medical treatment are not entered into a careful diagnostic approach but are responded instead with social measures.

If we are to provide proper care to our elderly patients, we must not neglect those conditions which appear incorrectly to be untreatable at first glance. Diogenes syndrome is one of these. To quote from Professor Burton V Reifler of North Carolina, "How we approach patients with severe self-neglect is an indication of what makes geriatricians different, and it reflects certain personality characteristics to be found in those among our ranks, notably patience, creativity, and empathy....In medicine there is nothing quite as exciting as treating those thought to be untreatable\(^5\).

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