Community study of people who live in squalor

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Summary

Background The reasons why people live in squalor have been the subject of much debate but little systematic research other than reports of case series from secondary health-care services. We did a study in the community using standardised instruments to investigate the relation between squalor and mental and physical disorders.

Methods We did a cross-sectional study of the clients of a local-authority special cleaning service. Levels of domestic squalor and self neglect were measured with the living conditions rating scale, and diagnoses of mental disorder were made by use of WHO's schedules for clinical assessment in neuropsychiatry (SCAN).

Findings 91 individuals were eligible for inclusion; 81 from 76 households consented and were interviewed (a response rate of 89%). 41 (51%) were younger than 65 years of age. 57 individuals (70%) were diagnosed as having a mental disorder at interview, as defined by the SCAN, and 21 participants (26%) had a physical health problem which contributed significantly to the unclean state of their living environment. Those with a contributory physical disorder had a lower severity of domestic squalor. People older than 65 years were less likely to have a mental disorder than those younger than 65 years, but a contributory physical disorder was not associated with the presence of active mental disorder. Only 30 (53%) of the 57 individuals with active mental disorder had had any contact with mental-health services in the previous year.

Interpretation People who live in squalor and who receive special cleaning services have high rates of mental disorder, and squalor affects younger as well as older people. Living in squalid conditions in the group was generally associated with a mental or physical disorder, and there were possible deficits in the health care received. The extent to which these disorders might respond to more assertive treatment from health services requires further study, but questions are raised about the adequacy of their current health care.

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Introduction

William Beveridge identified five giants to be slain on the road to reconstruction after the Second World War: want, disease, ignorance, squalor, and idleness.[1] Of these, squalor has probably been the subject of least systematic study. In 1966, Macmillan and Shaw described "senile breakdown in personal and environmental cleanliness" in a prospective study of 72 people living in squalor who had been referred to a specially established psychiatric unit over a 3-year period.[2] Almost all were over 60 years old; 53% had a mental disorder. The researchers concluded that personality, alcoholism, and bereavement were implicated in this behaviour. The term "Diogenes syndrome" was coined in 1975 by Clarke and colleagues, who described 30 geriatric patients admitted to hospital in a state of severe self-neglect, and who were living in gross domestic squalor.[3] The patients' lack of concern for their appearance and living conditions prompted the reference to Diogenes of Sinope—a cynic philosopher of 4 BC who lived in a barrel, eschewing material possessions. Although they did not operationalise the syndrome, Clark and colleagues reported that half the group had no mental disorder,[4] that they were of above average socioeconomic status and intelligence, but that they had personalities characterised by suspiciousness, aloofness, hostility, and unfriendliness. The investigators suggested that the syndrome might be a reaction of a certain personality type to stress in later life.

Since these early reports, the nature and name of the syndrome have been the subject of debate[5–7] but little systematic study, other than further case reports and series. One case series described 29 old-age psychiatric inpatients who presented over 2 years, and who fulfilled "criteria for Diogenes syndrome of extreme self neglect, gross domestic squalor and social withdrawal".[8] Two-thirds were clinically diagnosed with a mental disorder (including dementia, schizophrenia, and alcoholism), and most were single or widowed, living alone, and from lower socioeconomic groups. All studies to date have relied on referrals to specialist health-care services, so the data obtained are likely to be subject to ascertainment and referral bias (eg, studies of services for the elderly exclude consideration of squalor in younger people). Variation has been reported in the nature and degree of mental disorder, sociodemographic status, physical disorder, and cognitive function of those living in squalor. This variation will depend on the populations studied, but also on measurement error, since no study has yet used operationalised diagnostic criteria and standardised measures. We therefore did a study in the community using standardised instruments to investigate the relation between squalor and mental and physical disorder, and the extent to which the characteristics of people living in squalor accord with the concept of Diogenes syndrome.

Methods

Study population

Lewisham is the seventh most deprived inner London borough

Characteristic	Number of individuals (n=81)
Age group (years)	
18–34	5 (6%)
35–44	6 (7%)
45–54	13 (16%)
55–64	17 (21%)
65–74	17 (21%)
75–84	17 (21%)
≥85	6 (7%)
Sex	
Male	58 (72%)
Female	23 (28%)
Social class	
I	0
II	3 (4%)
IIIN	16 (20%)
IIIM	11 (14%)
IV	15 (19%)
V	28 (35%)
Unknown	8 (10%)
Household composition	
Lives alone	68 (84%)
Lives with partner	9 (11%)
Other	6 (7%)
Marital status	
Living as married	11 (14%)
Single, never married	44 (54%)
Widowed	13 (16%)
Divorced or separated	13 (16%)
Financial support	
Incapacity benefit	42 (52%)
Old-age pension	31 (38%)
Unemployment benefit	5 (6%)
Unable to determine	3 (4%)
Referrer to special duty team	
Social services	49 (61%)
Health services	17 (21%)
Housing	9 (11%)
Self or neighbours	4 (5%)
Missing data	2 (3%)

Table 1: **Sociodemographic characteristcs of individuals living in squalor**

Diagnostic category	Without substance abuse	With substance abuse	Total
Organic mental disorders			
Dementia	8 (10%)	5 (6%)	13 (16%)
Organic personality/behaviour disorder	0	2 (2%)	2 (2%)
Amnestic syndrome	0	1 (1%)	1 (1%)
Unspecified	0	2 (2%)	2 (2%)
Total	8 (10%)	10 (12%)	18 (22%)
Schizophrenia, schizotypal, and delusional disorders			
Schizophrenia	6 (7%)	6 (7%)	12 (15%)
Schizoaffective disorder	2 (2%)	1 (1%)	3 (2%)
Delusional disorder	2 (2%)	0	2 (2%)
Total	10 (12%)	7 (9%)	17 (21%)
Substance abuse			
With no other mental disorder	0	8 (10%)	8 (10%)
Total alcohol abuse	0	22 (27%)	22 (27%)
Total drug abuse	0	4 (5%)	4 (5%)
Affective disorders			
Bipolar affective disorder	1 (1%)	0	1 (1%)
Depressive disorder	3 (4%)	0	3 (4%)
Total	4 (5%)	0	4 (5%)
Neurotic and somatoform disorders			
Agoraphobia	2 (2%)	0	2 (2%)
Anxiety/depressive reactions	2 (2%)	0	2 (2%)
Generalised anxiety disorder	1 (1%)	0	1 (1%)
Total	5 (6%)	0	5 (6%)
Learning disability and developmental disorder			
Total	8 (10%)	1 (1%)	9 (11%)

Table 2: **Frequency of diagnoses of mental disorder and learning disability, and comorbidity of substance-abuse disorders**

with a population of 238 000 (34 000 of whom are ≥65 years). As do other local authorities, Lewisham employs a special duty team, who clean the homes of people living in squalid conditions. Cases are referred by social services, housing services, health services, and the public. The special duty team cleans on a one-off basis or regularly, depending upon need. The study population consisted of all clients seen by the team between November, 1996, and October, 1997. A research worker accompanied the team and, if they consented, individuals were interviewed at the time of cleaning or as soon after as possible. Where the household contained more than one individual, all were interviewed. Further information was obtained from social services, primary and secondary health services, and other informants, if available.

Methods

Sociodemographic data were collected, along with service use and attitude to current living conditions. Psychiatric disorder was assessed by means of the schedules for clinical assesment in neuropsychiatry (SCAN);[9] these schedules examine mental state with operationalised criteria, and produce diagnoses according to the International Classification of Diseases (ICD-10) by application of a computer algorithm. Severity of physical disorder and disability caused by acute and chronic illnesses were assessed and recorded systematically.[10] We judged that there would be a lack of informants to give collateral history; personality was therefore assessed with a self-report version of the standardized assessment of personality.[11]

To measure level of squalor systematically, the living conditions rating scale (LCRS)[12] was completed by the special duty team or the researcher, depending on who had first contact with the participant during the study period. Where both saw the client at the same time, the researcher's scores were used for analysis. The LCRS is derived from published criteria,[2,3] and has been used in a study of the clients of community health workers.[13] The scale has 20 items; 13 measure the interior environment (the interior scale): accessibility, odour, lighting, floors/carpets, walls, furniture, kitchen, food, bathroom/toilet, disposal of excreta, hoarding, clutter, and vermin. Four items measure personal hygiene and self neglect (the personal scale): skin, hair, finger/toenails, and clothing. Two refer to the exterior of the household (exterior of house and garden), and one to utilities. Each item is scored from zero to 3 by means of operationally defined criteria, where zero indicates acceptability of a problem, and 3 means that conditions are severely abnormal (eg, score of 3 on the furniture item is described as "filthy—cigarette burns, stained with food, urine, and faeces, and with all rooms affected").

Statistical analyses

Data were analysed by means of the statistical package for the social sciences. Associations of interest were examined with χ^2 tests for categorical variables, and t tests for continuous variables; multivariate analyses of association were carried out with logistic regression for binary variables and with linear regression for continuous variables.

Results

Participants

The special duty team had 28 regular clients at the start of the study, and there were 73 referrals during the study period (56 new, 17 re-referrals). Three new referrals were excluded, since the special duty team judged that they did not require special cleaning. Seven died before assessment, leaving 91 individuals eligible for inclusion; 81 (25 regular clients, 56 referrals) from 76 households consented and were interviewed—a response rate of 89%. Of the ten individuals from whom consent was not acquired, four refused to take part, four were not located, and two had moved and were not contactable. Sociodemographic data are presented in table 1.

Figure 1: **Living room of a 58-year-old unmarried man with paranoid ideas but no mental disorder**

Participants were aged 18–94 years (mean 63 years [SD 16]); 41 (51%) were younger than 65 years. 58 (72%) were male, and 68 (84%) lived alone. None were in employment at assessment and there was a preponderance of lower socioeconomic groups (assessed by application of the Office for National Statistics classification to the highest level of previous employment). 21 (26%) lived in bedsit or studio accommodation (single room with built-in kitchen and bathroom facilities), and seven (9%) in supported accommodation. Almost all (76 [94%]) rented accommodation from the local council or housing associations; four individuals were owner-occupiers, and one rented privately.
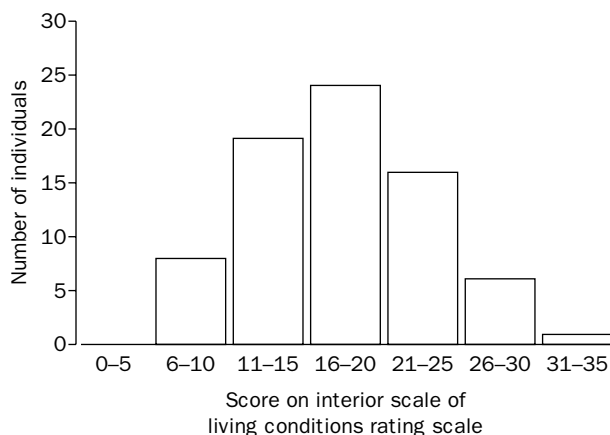

Figure 2: **Distribution of scores on the interior scale of the living conditions rating scale**
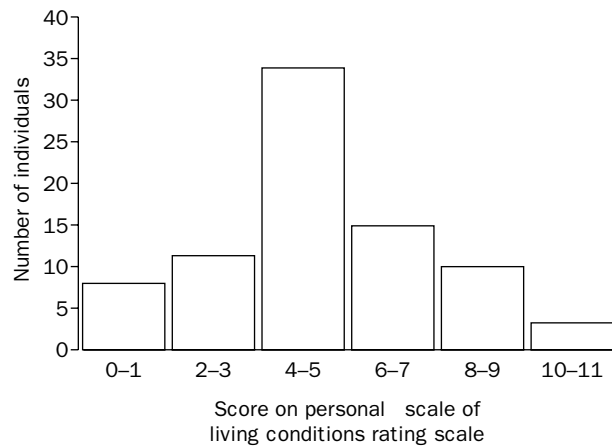

Figure 3: **Distribution of scores on the personal scale of the living conditions rating scale**

57 (70%) individuals were classified as having an ICD-10 mental disorder at interview, as defined by the SCAN. The SCAN allows for a diagnosis of substance abuse to be made alongside that of other mental disorders. There was high comorbidity between substance abuse (almost always alcohol abuse) and organic and schizophreniform disorders, but not between substance abuse and affective, neurotic, or somatoform disorders or learning disability (table 2). 14 individuals were classified as having an anxious/avoidant personality; five were paranoid/schizoid; one was dissocial; one was dependent; and ten were anankasitic (conscientious, perfectionist, and house-proud). Although 67 individuals (83%) reported leaving their house and interacting with other people, only 41 (51%) had someone in whom they felt they could confide. The remainder had regular interaction only with professionals involved in their care. A quarter had been visited by relatives in the last year.

Living conditions
Houses were often cluttered with bags and boxes of property and possessions so that it was virtually impossible to move around, with rooms inaccessible or impossible to enter safely. We commonly found all floor space thickly covered with newspapers, cardboard, discarded packaging, and other rubbish (figure 1). Often the occupant had accumulated or hoarded a large number of singular items such as milk bottles (sometimes containing souring milk), newspapers, food containers, carrier bags, or fabric. Several homes were dirty and unhygienic due to incontinence or blocked and overflowing toilets. Less striking but not uncommon were rooms and bedsits that were sparsely furnished except for a foul smelling sofa or mattress, and floors and tables that were thickly covered in dirt, dust, and rotting food.

The exterior scale of the LCRS was not completed since individuals were generally not responsible for the maintenance of the garden and exterior of their accommodation. The mean LCRS interior scale score (of a maximum of 39) was 17 (SD 6, range 6–34; figure 2). LCRS personal scale scores ranged from zero to 11 (of a maximum of 12); the mean score was 5 (SD 2; figure 3). Minor, moderate, or severe hoarding was present in 40 (51%) households. Hoarding was defined as an accumulation of singular items such as newspapers, bottles, or plastic bags.

23 individuals (28%) regarded their home as "clean" or "very clean"; 46 (57%) thought they were "dirty" or "very

Number of criteria met	Active mental disorder		No active mental disorder		Total
	Contributory physical disorder	No contributory physical disorder	Contributory physical disorder	No contributory physical disorder	
One	0	1	0	0	1 (1%)
Two	1	4	1	3	9 (11%)
Three	7	11	3	4	25 (31%)
Four	2	17	5	5	28 (35%)
Five	2	12	1	3	18 (22%)

Table 3: Number of criteria for Diogenes syndrome met, and variation by presence of active mental disorder and contributory physical disorder

Variable	Assocation with LCRS interior scale scores		Association with having active mental disorder	
	Regression coefficient (95% CI)	p	Odds ratio (95% CI)	p
Number of diogenes syndrome criteria met	3·83 (2·58–5·08)	<0·001	1·54 (0·68–3·49)	0·300
Age over 65 years	0·40 (−1·78–2·59)	0·714	0·32 (0·11–0·94)	0·037
Contributory physical disorder	−0·27 (−6·10–1·15)	0·005	0·44 (0·13–1·53)	0·197
LCRS personal scale score	−0·16 (−0·50–0·42)	0·869	0·96 (0·77–1·20)	0·726
LCRS interior score	··	··	0·96 (0·84–1·09)	0·529
Active mental disorder	−0·69 (−3·08–1·69)	0·564	··	··

Table 4: Multivariate associations with LCRS interior scale scores and with having mental disorder

dirty", and 12 (15%) were unable to answer the question. 15 (19%) were "not at all concerned" about the state of their accommodation, and 50 (62%) had such concerns; 16 (20%) were unable to answer this question. 14 individuals (17%) did not believe that their home was any less clean than those of other people of their age, 49 (60%) believed it to be equally clean or dirtier, and 18 (22%) were unable to answer the question.

69 individuals (85%) had at least one chronic physical illness, and 17 (22%) at least one acute physical illness at the time of interview. Chronic illnesses were generally mild to moderate in severity, but in 37 (46%) individuals, they were moderately or severely disabling. 54 (67%) reported taking prescription medication regularly, including 24 (30%) who took prescribed psychotropic medication. 21 individuals (26%) were rated as having a physical health problem such as incontinence, immobility, or severe visual impairment which had significantly contributed to the unclean state of their living environment.

24 individuals (30%) received services at home other than those of the special duty team. 74 (91%) reported having a general practitioner, and 65 (80%) had consulted him or her in the preceding year. Only 30 (53%) of the 57 individuals with active mental disorder had had any contact with mental health services in the preceding year.

Diogenes syndrome
We operationalised the criteria for Diogenes syndrome as follows: presence of domestic squalor; evidence of self neglect (LCRS personal score ≥4); living alone; a tendency to hoard (any evidence of hoarding); and a lack of concern for surroundings (being "a little" or "not at all concerned" about the state of their accommodation). 18 individuals (22%) met all five criteria for Diogenes syndrome. However if a sixth criterion, absence of active mental disorder, was added as has been suggested,[3] only four (5%) people met the criteria (table 3). The proportion of individuals with mental disorder increased as the number of criteria met for Diogenes syndrome

increased, but the proportion with a contributory physical disorder did not increase in this way. This finding suggests that fulfilment of criteria for Diogenes syndrome is associated with mental rather than physical disorder.

Gender, age, attitude to the need for cleaning, and the presence of mental illness were not significantly associated with severity of squalor. Table 4 presents the results of modelling associations with LCRS interior scale scores by multiple regression, controlling for other variables of interest. There was a negative association with contributory physical disorder and a positive association with number of Diogenes-syndrome criteria met. Modelling associations with mental disorder by logistic regression, people aged 65 years or older were less likely to have a mental disorder than people younger than 65 years, and contributory physical disorder was not associated with the prevalence of an active mental disorder.

Discussion

The main findings of this study were that people who live in squalor and who receive special cleaning services have high rates of mental disorder, and that squalor affects younger as well as older people. In addition, squalid living conditions were more likely to be associated with mental or physical disorder than with the narrowly defined Diogenes syndrome.

The main study limitations were due to its cross-sectional design and the use of individuals seen by the special duty team as the sampling frame. The cross-sectional design does not allow ascertainment of direction of causality, so we can report only associations. In the absence of an adequately powered cohort study or an appropriately designed case control study, along with the current lack of data available, we suggest that our approach is a useful start. The study participants were a referred group and so may differ systematically from people living in squalor but who are unknown to the special duty team. This was, by design, a study of people in their own household, rather than of squalor in homeless individuals. The latter is an important area for further study, but not one which can be directly addressed by the data generated from our study.

We identified a range of psychiatric diagnoses including high levels of serious mental illness such as schizophrenia and dementia. The large group of people with learning disabilities living in squalor is of particular concern. In addition, this study illustrates the importance of comorbid alcohol abuse in those with organic disorders and schizophrenia. We found no case where clutter or hoarding was a function of formal obsessive compulsive disorder, and only a few where there was potentially explanatory impairment of executive and other frontal-lobe function in the context of an organic mental disorder.[14] Although the measurement of personality was difficult in this group, owing to a lack of informants, the personality types predominantly identified (anxious or avoidant, anankastic) may point to a role for obsessional traits in the aetiology of squalor. The low rate of depressive disorders suggests that living in squalor is not commonly a function of the psychomotor retardation and apathy of severe depression.

Unlike earlier reports, the individuals we identified were predominantly male. This finding may reflect our inclusion of younger people with mainly functional psychoses. Our findings do not accord with the

description of people with Diogenes syndrome as having "led successful professional and business lives, with good family backgrounds and upbringing".[3] This difference may be due to referral bias in the populations previously described, and the general exclusion of younger adults in other studies. We have been unable to find any previous study that examined the attitudes of people living in squalor to their own living conditions. One third of our sample reported that their home was clean or very clean. This finding suggests that the participants had a sense of awareness of the nature of their environments, and perhaps a judgment or tolerance different from that of people who live in cleaner settings.

In this specialist social-service contact-group there were possible deficits in the receipt of health care: 26% had a potentially contributory physical disorder, and only half of those with active mental disorder had had any contact with psychiatric services in the last year. Some may suggest that these individuals would be difficult to engage and treat; however, our ability to interview them as part of this study, and the fact that they were willing to accept help from the special duty team, suggest that such negative preconceptions may be unfounded. There is a need for further work to assess the level of unmet needs in this population, and to develop ways of meeting these needs.

Few of our study group accorded with the classical description of Diogenes syndrome. We found that severity of squalor increased with the number of criteria for Diogenes syndrome met; that there was a lack of explanatory physical illness; and that mental disorder in people living in squalor was less common in older adults than in younger people. In particular, there may be differences between squalor of physical aetiology and squalor of psychiatric aetiology. 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,[14] rather than as a rare syndrome due to reclusiveness or an eccentric personality. The term Diogenes syndrome may have been in use in raising the issue of squalor, but the syndrome does not cover most of those we studied. In addition, the focus on domestic squalor being a function of Diogenes syndrome may have diverted attention from squalor as an important public-health problem in itself. Our results suggest that "Diogenes syndrome" should be regarded as a term of historical interest rather than of clinical utility.

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