

SEVERE DOMESTIC SQUALOR

By John Snowdon. November 5, 2009

Introduction

[SLIDES 1, 2] I want to talk about this word 'squalor'. What's it mean? Is it the right word for what we are talking about? What is severe domestic squalor? How should we respond if we encounter cases in our community? Why do some people come to live in severe squalor? What factors are associated with living like that? What's the incidence? What's the prevalence? And that will lead up to the most vital question? What can we do about it?

Squalor: what does the word mean?

[SLIDES 3, 4, 5] Most of you have seen and walked through dwellings that you've thought were very unclean. The term 'severe domestic squalor' has been used in cases where observers describe unacceptably filthy, unhygienic and sometimes nauseatingly disgusting living conditions.

I want to confront you with this word, 'squalor'. Is it pejorative? Is it stigmatizing? Is it appropriate?

If you look at the synonyms for 'squalor', you'll find dirtiness, filthiness, foulness, griminess, grubbiness, uncleanliness and even 'sordid dirtiness'. Squalor is "a state of being extremely dirty and unpleasant, especially as a result of poverty or neglect" (says the Oxford Dictionary). In another dictionary I was offered two alternatives: "shabbiness and dirtiness resulting from poverty or neglect" and (wait for it) "moral degradation".

In describing the sort of cases that I have in mind, you and I would be horrified if we thought we were being understood as saying that those living in such conditions were living in states of 'moral degradation'. You and I are not saying that. We make no judgements about morals or about being 'degraded'. Nor do we want poverty in our definition, even if it's sometimes a factor to consider. The risk of being misinterpreted makes us hesitate before using the word 'squalor'. But what other term succinctly describes what we observe in the cases we're talking about? I put it to you that we should not pussyfoot. In order to impress governments and people in general about the need for action and taking responsibility in such cases, we need to say it how it is. We are talking about living conditions that are unacceptably unclean, unsafe and/or unhygienic, and that have unacceptably deleterious effects on the people living there or nearby.

We do not use the term 'domestic squalor' to describe people. We use it to describe living conditions. If we're being confronting it's in relation to domestic environments rather than to the people living there, though often the associated but unspoken thought is

“How could people live like that? How have they allowed their living conditions to deteriorate in that way?”

Should we do something when confronted with squalor situations?

The most important part of this conference will be a consideration of how and when to intervene in cases of severe domestic squalor. First I want to ask what others can or should do if they find the living conditions of a neighbour or member of their community are getting into an undesirable state, through a person’s disability or for whatever reason. Who can we go to if someone’s at risk? Who’s in a position to take action, and do they care about such things?

Did anyone see the film ‘The Young Victoria’? I’m not sure of its historical accuracy, but other writings have confirmed what it reflects about one of Queen Victoria’s Prime Ministers, Lord Melbourne. He was a trusted adviser, and was portrayed as saying the poor and their conditions should be ignored. It gave him discomfort if he encountered people living in harsh conditions, in slums, in squalor – so he chose to focus on other things, and advised Queen Victoria to do the same.

It was because of such attitudes among politicians, and those in a position to intervene, that Charles Dickens, Balzac and others drew word pictures to provoke the consciences of their readers. Dickens, in ‘Oliver Twist’, wrote of “rooms so small, so filthy, so confined, that the air would seem too tainted even for the dirt and squalor which they shelter,... and dirt-besmeared walls and decaying foundations, every repulsive lineament of poverty, every loathsome indication of filth, rot and garbage; all these ornament the banks of Folly Ditch.”

Dickens also wrote about Miss Havisham in ‘Great Expectations’, who lived in an unclean environment – but I mustn’t get ahead of my theme.

Something was done about the slums of London. On the whole, English streets are clean. So are Australian environments – on the whole. We’ve got people who discard litter carelessly, and you wonder if they’d do the same in their own homes and gardens. Mostly, except for one household in 300, we’re clean enough.

But I want to stick to a theme about responsibility to intervene. There are countries where awful squalor can be observed. Some people in those countries might get upset that they are being singled out. They might ask what right we have to express ourselves disparagingly about their environments. I don’t want to name cultures or communities – except that in one case it’s been paraded around the world, and that’s the squalor in Mumbai. [SLIDES 6, 7] ‘Slumdog Millionaires’ had major messages, equivalent to those Dickens tried to get across. Some people live in unhygienic, unhealthy, dispiriting conditions, and what’s being done about it? Homes of the rich are OK – we see that in the film. In other areas of the city the streets are full of garbage.

I've been to three other countries where particular areas are known for the squalor in the roadways. One I'll describe. We drove from one city to another along a major highway. There was filth in the open drains, and all along the sides of the roads there were mounds, truck-high banks of garbage. Discarded water-bottles and packaging and anything you can think of. In the second city I went on a home visit with the community old age psychiatry team, along rubbish-strewn roads, across streams and rivers that were blocked by garbage. There was a smell, of course. The man we were visiting had mild dementia and the floors of his dwelling were clean. Lots of flies, though – they'd flown in from the garbage heaps.

How can it be? Major highways, major cities. What have their governments done about it? Well, they've tried. I read parts of a government report relating to waste management in that province. "The uncontrolled disposal of liquid waste into open gutters, open spaces, along roads, etc., poses serious health hazards. Bodies of stagnant water produce bad odours..." The report was ten years old. Various governments in that country had not been able to get control; money had been mis-spent. To my senses, the squalor was disgusting. It's not the people I criticize. It's the system. Why had those with power, influence and money failed to act? Neglected to do enough to reverse the cycle. More rubbish being thrown on to the streets than was being collected by garbage workers? Neglected to pay the garbage workers, maybe? By using the words 'severe squalor' I think I'll have conveyed a picture to you.

I propose to use the words 'severe squalor' in relation to domestic situations that are equivalently in need of attention. I suspect such cases have been in our midst for centuries, but they weren't written about in health-care literature until the late 1950s. When discussed, it's been evident that attempts to intervene have commonly been poorly coordinated and unsupported by those in a position to help. We believe there's now reason for optimism about giving appropriate attention to cases of severe squalor in our communities – the one in 300 households that we'll discuss shortly.

One more thing about squalor in Mumbai and other Indian cities, and the three countries I've alluded to. Companies have been organizing tours to these places. It's been called 'poverty tourism', or 'poorism' or 'slum safaris'. Is it appropriate or not? Do the tourists go there to see the environments or to see how people react to those environments? Do these tourists visit squalor environments to marvel at a spectacle, at displays, like visitors to madhouses in the 19th century, or to the zoo? Or do they go in order to learn and consider how people in need can be helped? The latter is what the tourist operators argue.

And when you and I go to see someone living in severe domestic squalor, is it to marvel? When we look at spectacles in television segments, or in photos or films, is it like going to a horror movie, to shock ourselves and know that we can turn away at the end of it? Or do we do so because we do care, we don't want to turn away, and we want to learn in order to ensure that society and politicians do not turn away? One photo I saw of crowd reactions to 'Slumdog Millionaires' and its producers showed a banner: "We need love, not humiliation".

It is important that we examine what we are doing and why we are doing it, at this first-ever conference about severe domestic squalor.

What is severe domestic squalor?

I repeat: the major aim of this conference must be to foster improved understanding of when and how best to intervene in cases of squalor. We will be discussing the rights of individuals to live as they please – and the responsibilities of others to do something if a person's habits or behaviour are causing significant harm to themselves or others.

Let's start by considering a 26-year-old woman who collects newspapers and magazines, and whose home I visited. She told me of the difficulty she has in deciding when or whether to throw away the newspapers and magazines. Her subconscious says it's a waste to dispose of them. There's lots of information in them. It might be useful. In time, her unit is full of piles of publications and the piles begin to coalesce and grow taller. She is embarrassed to invite anyone in; she no longer lets family members call. She tries to resist the urge to collect more, she tries to throw things away – but it all gets on top of her. The piles are dangerous, both as a fire-hazard and because they may fall on her. She can't keep the place clean, so vermin add a health threat. She's depressed. She becomes less competent at her work. Her job's at risk. She needs help – but can't decide whether to admit to the problem.

Who should do what? We can hope that someone assertively takes action in such cases. Hers is a condition that in the right hands can be cured or at least controlled. Most cases of severe domestic squalor aren't so easy to formulate or deal with. What should we do in cases where the occupant won't let us in, won't go along with our proposals for intervention – and where we're sure we can get them out of the cycle that leads to uncleanliness? But what do we do if the occupant says "No thank you, nothing needs to be done and I don't want anyone intervening?" That's for discussion later in this conference, when we refer to guidelines for intervention – but understanding of factors leading to the squalor, and differences between squalor situations, will help us work out how best to intervene.

Some of you may never have encountered cases of severe squalor. They vary. The example given by Cooney and Hamid (1995) [SLIDE 9] is a bit different from that of the 26-year-old I've just mentioned.. They referred to "a reclusive, elderly person, living alone in a dilapidated filthy house. The house is cluttered with rubbish and infested with vermin. Excrement and decomposing food are strewn around the floors and the stench emanating is unbearable to all but the occupant, who is blissfully unconcerned by the situation".

‘Severe domestic squalor’ isn’t a diagnosis. It is a description of the appearance and perceptions of a dwelling. There is usually a complex admixture of reasons why a person, a couple or group of persons, is living in such conditions – and I’ll address some of them. But cases differ a lot. And broadly we can start by dividing cases in two ways. [SLIDE 8] One is in terms of severity. Just how filthy or grimy or messy is the dwelling? Mildly, moderately or severely? We can rate this on the Environmental Cleanliness and Clutter Scale, the ECCS (Halliday and Snowden, 2009). The other relates to the extent of clutter/hoarding/accumulation of items, VERSUS accumulated mush, muck, filth, rotting food, garbage, human and animal excreta – the latter may be more nauseating – but access through the dwelling, ability to walk around, isn’t so restricted in such cases, providing we don’t mind what we step in or over.

In half or more of the cases referred to health or community services, there has been progressive accumulation of items of little or no monetary value. The items may be rubbish – discarded containers, tins, bottles, boxes, packaging – discarded in the dwelling but not disposed of. Or freely acquired newspapers. Or freely acquired anything. Or purposely acquired but unneeded. So, like the 26-year-old’s home, stuff accumulates. It may be that the person knows he or she has got too much already, but mostly they don’t agonise about what should be discarded. They don’t so much have an urge to collect. It’s become a habit they don’t try to resist. Electrical goods, things that might come in useful to someone some day. These aren’t so clearly obsessive-compulsive cases, though a lot will be deemed to be compulsive hoarders. They don’t see a need to be helped, unlike the 26-year-old.

There are others who live in squalor but who don’t accumulate items in the way that so-called hoarders do, but they don’t clean either. They don’t discard rubbish. They may not recognize that a toilet is the appropriate receptacle in which to defaecate or urinate – or maybe they have such urgency that they soil parts of the dwelling. And then don’t clean it up. Their homes are just as filthy as those of people whose accommodation is very cluttered – but it’s a different sort of squalor. And maybe they have animals that aren’t prevented from excreting inside the house. Can be very messy!

However, it’s not a clear-cut division between what Graeme Halliday has called dry squalor and wet squalor. I’m thinking of a man with accumulated rubbishy items and stuff preventing access to most parts of most rooms, yet the kitchen and fridge were completely unhygienic and filthy, his bed was stained and covered with you-know-what, and the yard was deep in dog faeces. I won’t describe his toilet, but I’ll tell you I retched. Our rating on the ECCS was 28/30. When people hoard animals as well as other stuff, the resultant squalor can be described as a mixture of wet and dry.

Let’s look at some photos, some collected off web-sites, some taken in Sydney.
[SLIDES 10 - 38]

What can we conclude from such photos? Firstly, there’s a range of squalor situations. Some people live in filthy homes without a lot of clutter. Some live in very cluttered dwellings that can’t be cleaned because of the clutter.

Some people living in squalor recognize that their places are unacceptably dirty and may make an effort to do something about it. [SLIDE 39] Most don't recognize a need, let alone an obligation, to get rid of the rubbish, or the desirability of having others come and help clean up. They may show a lack of concern, they may keep themselves apart from others socially, they may be loners, they may be hostile to those who intrude on their space or seem to want to provide help (they don't perceive a need for assistance or change) – they may stubbornly refuse help. But cases vary. We need to understand the individual when considering whether and how to arrange interventions. Some may be glad to see us, they may be friendly and may show insight. We need to try to understand the various factors that may have led to them living in squalor, before we start intervening.

Why do some people live in squalor?

What do we know about WHY some people live in squalor? What's the evidence? If we know why, maybe we can stop it developing in the first place. Is there anything we can **treat** so that the person stops neglecting care of their environment, or stops bringing in stuff that makes cleaning impossible? Or is there nothing treatable – in which case we may well need to provide help in maintaining cleanliness on an ongoing basis, if we think cleanliness matters.

So – why?! During previous centuries, people have described cases of squalor – in novels, non-fiction books, newspaper reports – so we know it's not a new phenomenon. We've heard of hermits who didn't wash and didn't care about appearances. We get an impression from Dickens and others that squalor is commonly a result of poverty and miserable conditions – though not always: think of Miss Havisham and her cobwebbed, duster-deprived living rooms. Mild, dry squalor, maybe? It does seem that neglecting care of surroundings is commonly an accompaniment of self-neglect (the term used when people neglect proper care of their person).

But let's consider other possible explanations for why people might live in squalor. Is it possible that some people don't clean up because they're just plain lazy? Is it possible that some people don't clean up because they've lost the skill and motivation – maybe through mental or physical disorder? Is there any evidence?

The first attempts to **research** such problems that were documented in health-related journals were by Shaw in 1957 and then in 1966, working with Macmillan, and they used the term 'social breakdown in the elderly' when discussing a series of cases of people living in severe squalor. They referred to a breakdown in standards of personal and environmental cleanliness, and they commented that in some cases "the patient cared for her person but not for the environment".

Roughly at the same time, Granick and Zeman (1960) in New York commented on the lack of research concerning hermits and recluses. They noted general public interest in

the mountains of trash (136 tons of junk) that filled the house of the Collyer brothers, the hermits of Harlem, who died in 1947. One brother was an engineer, the other trained as a lawyer. [SLIDES 40 - 42] One was suffocated by the garbage that cascaded down upon him. The other, blind and paralysed, died later of starvation. But however fascinated the public might have been at the time, the case didn't lead to any serious research concerning such recluses. Maybe it was felt inappropriate to intrude on their lives, even if the reclusive life might sometimes lead to disasters. Granick and Zeman did show interest. They found 105 newspaper articles each reporting circumstances that had led to the death of someone described as a recluse. 47 of the articles described the deceased person's home: 39 of the 47 had lived in shambles, unkempt or dingy homes piled with trash. Yet most left estates of over \$30,000 – this was prior to 1960. Yes, a very selected sample, I'm sure, but confirming that living in squalor does not necessarily mean being very poor.

The cases described by these researchers, and later by geriatricians Clark et al (1975) when they suggested the term 'Diogenes Syndrome', referred to elderly people, so some started talking about a Senile Squalor Syndrome – inappropriately implying that squalor is age-related. Halliday et al (2000) in their study demonstrated that over half the people living in housing in South London for which heavy-duty cleaning was needed because of unacceptably filthy living conditions were not elderly.

In the last 50 years, studies of series of cases and a number of individual case-histories have provided a broad picture of people in various countries who had been reported as living in squalor. Most provided details about whether subjects showed evidence of having **mental disorders**, and about factors that might have affected their lifestyles and living conditions. In a review published two years ago (Snowdon et al, 2007), we drew conclusions based on studies and reports concerning over 1100 people living in domestic squalor, but we were also aware of a complementary body of literature that focused on hoarding rather than on squalor or uncleanliness. We were aware that cases of squalor where purposeful collection of items had been perceived as the major problem, and where a psychologist's help was favoured as the first option for intervention, were less likely to be referred to health services for intervention – so they'd be less likely to be included as case-reports or among series of cases of squalor they published in medical journals. [SLIDE 43] Reports of series of cases of people who hoarded possessions provided no clear idea concerning the proportion of these subjects who could be deemed to be living in severe domestic squalor. Was it 20%, 50%, 80%? We don't know. We have encouraged those who might report on series of such cases in the future to use a rating scale to indicate the degree of uncleanliness as well as the degree of clutter. It's a question we could raise later in this conference, and one which we'd put to David Tolin and his colleagues in the U.S. and David Mataix-Cols in the UK, who have done so much in the last 15 years to highlight compulsive hoarding as a problem. It's clear, though, from various accounts, that not all people who hoard live in squalor. But some do, and it may be that conclusions about the pattern of mental and psychological disorders among people living in squalor will be inaccurate if derived mainly from medical literature.

Also in our review, we drew attention to Maier's (2004) questions about use of the term 'hoarding'. [SLIDE 44] Maier agreed with Frost and Gross (1993) that difficulty in discarding may be related to avoidance of decision-making. Some people with OCD collect too much and have difficulty discarding. Yes, that's hoarding. There are others who have difficulty with impulse control, and acquire more than they discard – it's an impulse-control deficit rather than a compulsion. Nevertheless, we can call this hoarding. However, when people collect ritualistically, stereotypically, and are indifferent to the removal of acquired objects, Maier prefers the word 'collectionism' rather than hoarding, to describe their 'grasping' behaviour. And when people accumulate rubbish and filth through lack of motivation or ability to throw it away, that should not be described as hoarding. We would expect published series of hoarding cases would be concerned with the first two of these four categories, and that diagnoses of OCD and compulsive hoarding would dominate, though maybe with mention of possible frontal lobe changes. Cases in the third and fourth categories would not be likely to be taken on by psychologists for treatment, and are much more likely to appear in the squalor literature as opposed to the literature focusing on hoarding.

I'll also mention self-neglect to make sure we're not over-inclusive when examining the incidence and prevalence of squalor situations, and when exploring why people come to live in squalor. [SLIDE 45] Some people write of severe squalor as being a form of self-neglect. It's true that the individual living in squalor neglects to clean up, to maintain hygienic living conditions, to prevent the hazards created by widespread filth. Neglect of domestic environment is indeed a way of neglecting aspects that can impact on the health and welfare of the individual, the self. It can also impact on the welfare of others living in the same environment – so it's neglect of self and maybe others. [SLIDE 46] But not all people who self-neglect in other ways (by not eating or drinking enough or appropriately, not exercising, not washing, not seeking help for medical problems) fail to maintain domestic cleanliness. And people who allow filth and rubbish to accumulate don't necessarily neglect care of themselves. So a review of factors associated with self-neglect doesn't help sort out which factors might explain why some persons live in squalor, and estimates of the incidence and prevalence of self-neglect aren't meaningful when considering how common severe domestic squalor may be.

Again let's pose the question: WHY do some people live in severe domestic squalor? Our experience in Central Sydney, Catholic Healthcare's experience, Graeme Halliday et al's findings in London using a structured diagnostic interview schedule, and the findings from those case series and reports I've referred to, show that a majority of people living in severe domestic squalor have a mental disorder or at least a psychological disorder. Others have a physical illness or disability, or a situational problem. Many have a combination of problems and/or disorders.

Susan Graham and colleagues will be able to report about mental and physical health problems across the age-range of people in Sydney who've been reported to them as living in squalor and needing help. Theirs, like other reported samples, is a biased sample, but we'll get an impression about how often drug abuse, schizophrenia etc are seen as causative or contributory conditions.

Halliday et al's findings (2000) regarding people, half of whom were middle-aged or younger, whose homes needed heavy-duty cleaning [SLIDE 47] show that the diagnostic pattern is unsurprisingly different to what's found if we look just at older people living in squalor. They reported that 70% of the 81 interviewed subjects had mental disorders: 22% had dementia or another organic mental disorder, 21% had schizophrenia or a delusional disorder, 10% had substance use disorder. 11% had a developmental disability. None had OCD, but 24 were deemed to have personality problems, either obsessive-compulsive or anxious-avoidant. 27% altogether abused alcohol.

In regard to older persons, I looked through our data-base [SLIDE 48] of 113 people aged over 65 years living in **moderate or severe** squalor who were referred to our old age psychiatry service in the 9 years from 2000 to 2008. In clinical (but unstructured) interviews, we diagnosed 40% as having dementia, some of these having psychotic ideation, some having fronto-temporal dementia. Another 20% had alcohol-related brain damage (ARBD) with cognitive problems or were persistently abusing alcohol. A further 13% had schizophrenia or delusional disorder. So that's 73% already. In 9% of cases, physical illness or disability appeared to be the major factor leading to a build-up of filth. We agreed that 9% of the 113 presented features pointing to their having personality disorders, half being labeled by us as showing compulsive hoarding; others were paranoid or eccentric but not clearly cognitively impaired. None of these elderly people had a history of Developmental Disability.

It would be good to ask Graeme Halliday and Susan Graham to compare the diagnostic patterns of the elderly subjects with those of the non-elderly in their samples.

Various features in cases of severe domestic squalor are also those of frontal lobe dysfunction. Social withdrawal, disinhibition, lack of empathy and concern for others, and reduction in personal hygiene and self-care are features of dementia of frontal type (Gregory and Hodges, 1993), and associations between hoarding and frontal lobe changes have also been reported. There is limited but growing evidence that frontal lobe dysfunction is a major factor accounting for severe domestic squalor – and this frontal lobe dysfunction could result from brain changes in progressive dementia, in ARBD, in schizophrenia, and indeed in OCD and when personality disorders are related to organic brain changes. Even when squalor occurs in association with medical illnesses, it may be that mood or personality factors related to brain changes are what determine whether a person is motivated to clean up their dwelling or contrastingly to accumulate items of little obvious value to them.

[SLIDE 49] Findings about the prevalence of mental and physical disorders in cases of severe squalor are relevant in thinking how best we can intervene when the state of a dwelling causes distress and problems for occupants and their neighbours. Some live in squalor because of a lack of motivation to clean up. Some because they over-acquire items and don't throw away, often due to indecision. There's a complex interplay...

Incidence, prevalence and demographic factors

How common is it and where do we find squalor? Estimates of the incidence and prevalence of squalor based on data from referral samples will be inaccurate, due to referral bias and varying understanding of the criteria for defining squalor and its severity. Although many of those living in squalor have been shown to have mental or physical disorders, referral to health services is not necessarily what they need in order to deal with their problems. Referrals may be made to cleaning services, decluttering workshops, or counselors unconnected with health services -- or to others who can help them achieve improvements in their situation. Even if interlinking of records gave us data about all squalor cases known to health or other agencies, estimates of squalor prevalence would probably be well below the true figure: some cases will not be reported. In isolated or sparsely populated areas, some cases may not be noticed. Some housebound individuals may live in squalor and may not be known to neighbours or people who could intervene. And there may be cultures and groups in this and other countries where build-up of what we call filth or rubbish is not regarded as noteworthy. I'd be interested to obtain comparative data regarding what's regarded as 'unacceptably unclean' in diverse places. Average Australian attitudes and ideas about cleanliness aren't necessarily right -- or optimal. But what matters is if squalor of a dwelling is potentially harmful or disturbing to the occupant or others. The prevalence of such cases needs to be known.

Objective measurement of aspects of uncleanliness and clutter can of course be made (for example, using the ECCS), and it would be interesting to know if such ratings would be feasible and useful in Mumbai and in villages where houses have dirt floors, as well as in Sydney. Adaptations would be needed to cope with situations where occupants use toilet and bathing areas and cooking facilities that are at some distance from their dwellings. Maybe the whole concept of domestic cleanliness needs adaptation, but we won't know until we've been able to talk about this with informed locals in those other places.

The ECCS allows ratings of access, and of accumulation of clutter, as well as 8 aspects of uncleanliness. [SLIDES 50, 51] Graeme Halliday and I tried to define anchor points, but of course one can't take everything into account. We'll be grateful for suggestions for improving the wording of ECCS items. Susan Graham has commented that we need to include more on clutter. We could, for example, have an item on ease of access to utilities, such as the stove, shower or washing-machine. We have found that a score of 13 or more out of 30 was usually indicative of what we deemed to be severe domestic squalor -- i.e. cases that require/need intervention. In fact, Graeme and I called some cases 'moderately severe' in order to distinguish them from the most severe, but even in moderate cases, the living conditions would seem to most people to be unacceptable, and therefore let's lump them all together using the descriptor 'severe domestic squalor'. We can report on the incidence of cases scoring 13 or more on the ECCS among older people in central Sydney.

Frost, Tolin and others have included questions on cleanliness in their evaluations of cases of hoarding, but not in a way that allows ratings of squalor. They have, however, developed scales to rate hoarding, and the latest and simplest is the Hoarding Rating Scale – Interview, an instrument consisting of 5 items (clutter, difficulty discarding, excessive acquisition, distress, and impairment), each measured on a scale ranging from 0 to 8. Scores of over 17 out of 40 were said to discriminate hoarding from non-hoarding cases (Tolin et al, 2009). This could be used with the ECCS when seeing people living in squalor, but note that the hoarding scale includes ratings of a **person's** perceptions of problems, difficulties and distress, whereas the ECCS is solely of the **observed domestic environment**.

Macmillan and Shaw (1966) estimated that the annual incidence of moderate or severe domestic squalor among elderly people around Nottingham, England, was 0.5 per 1000. We can comment on the incidence of cases referred to our old age psychiatry catchment area service in Sydney. In Central Sydney between 2000 and the end of 2008, we received referrals of 160 people aged 65 years or more who were living in squalor and who allowed us to visit [SLIDE 52]. This was from a population of 18000 older people living in their own homes in the area. On the ECCS, two thirds of them were living in moderate or severe squalor. About half of the cases of moderate or severe squalor were rated as showing little or no hoarding, and in 40% there was little or no clutter. [SLIDE 53] When followed up a year later, 66% of the 160 subjects we saw in the 9 years, and half of those rated on referral as living in moderate or severe squalor, were still living in their own homes. [SLIDE 54] The incidence of cases of **moderate or severe** squalor per year in this population referred to old age psychiatry was 0.7 per 1000, and we calculated the prevalence among older people (bearing in mind those still at home a year later, and some a lot longer) was 1.5 per 1000. The prevalence including referred cases of mild squalor was 2 per 1000. If we take into account all those cases referred to Mercy Arms and other community agencies, and to psychologists, and not referred to old age psychiatry, the incidence is probably a lot higher than the figure I've given you – and that's without taking into account all those that aren't referred to anyone! I'm sure Susan Graham's data from the squalor hotline project will confirm the high incidence and prevalence across Sydney.

The percentage of younger people who live in squalor isn't so high as the percentage of older people, judging by Halliday et al's figures. They found almost equal numbers of people under the age of 60 as over that age in their part of South London were living in premises requiring heavy duty cleaning.

Of over 1100 subjects whose gender was mentioned in case reports and case series in health sciences journals, but not including data from series of hoarding cases, 59% were female. Of Central Sydney referrals of older people, only 34% were female. Most of those living in conditions that we refer to as moderate or severe squalor lived alone, [SLIDE 55] though about 20% (living in moderate rather than severe squalor) lived with at least one other person. Nearly half our sample of people living in moderate or severe squalor lived in Department of Housing accommodation and an equal number were owner-occupiers. [SLIDE 56]

So the data suggest that about 1 in 500 older people live (mainly alone) in squalor ranging from mild to severe, and the proportion of younger people living in squalor is smaller. An unknown percentage of the population, including a number of younger people who abuse drugs, live in squalor but aren't known to services. Taking into account the average size of households, I'd hazard a guess that 1 in 300 households or dwellings would provide you with an example of domestic squalor. If you walk down three streets, each with 50 houses on either side, even in Vaucluse, you may notice at least one where the condition of the garden or yard suggests there may be marked uncleanness behind the front door. If you walk through a high-rise block of 300 apartments, you may detect (because of a smell or the cockroaches or flies or other clues) something to suggest unacceptable uncleanness behind at least one of the apartment front doors – more than one in some blocks. We can talk later about what the Department of Housing's responsibilities are to ensure their tenants are O.K. Whether occupants should be expected to do anything about perceived uncleanness will vary, as will the willingness of occupants to have anything done.

Conclusion

[SLIDE 57, 58] I've tried to give you a picture of severe domestic squalor and the range of cases we encounter. Rather different from the picture of Diogenes's dwelling. It is likely that those who live in squalor start doing so because of a complex interplay of triggers and vulnerabilities. Obsessive compulsive traits and indecisiveness may contribute. Apathy, impaired executive function due to brain disease or mental disorder may be blamed. Sometimes, squalor develops when people don't have physical or mental capacity to clean up. I've suggested that it is relatively common. The importance of considering why people live in severe squalor is that answers will help in planning strategies of management. Guidelines that help agencies to plan and coordinate interventions (such as those developed by our Reference Group with funding support from DADHC, the Department of Aged, Disability and Home Care) , and adequate funding to allow them to do so effectively, need to be tailored to local situations.