Diogenes Syndrome

A Geriatric syndrome of gross self neglect
Diogenes Syndrome

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Questions

- What is Diogenes syndrome
- How is it diagnosed
- Mortality if untreated?
- Management strategies?
- Social services that can help?
Diogenes Syndrome

A disorder of gross self-neglect
Learning points

- What is Diogenes syndrome?
- How is it diagnosed?
- Mortality?
- Management strategies?
- Social services that can help?
Case: Mr. J

- 85 yo man
- Divorced, former (?) Current) alcoholic
- Lives alone in a dilapidated house
Mr. J : PMH

- In hospital 2006 for CHF & PNA; behavior issues, while there → $D_x$ Fronto-Temporal Dementia
- also CHF, A-fib, leg ulcers, elevated lipids, renal impairments, aseptic necrosis R hip & BPH
- deemed competent → sent home

his re-involved son very worried about home safety
What is Diogenes Syndrome?
Diogenes: a syndrome of:
Diogenes: a syndrome of:

Extreme self neglect
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- Domestic squalor
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- Social Withdrawal / refusal of all help
Diogenes: a syndrome of:

- Extreme self neglect
- Domestic squalor
- Excessive hoarding
- Lack of concern / shame re: residential situation
- Social Withdrawal / refusal of all help
First medical description

- by Dr. Duncan McMillan (BMJ 1966)
- Case series: followed 72 persons, most elderly aged 60-92 (one was 48)
  - All living in deplorable circumstances, rejecting society, denying problems & resisting help
  - 50% had a mental health problem to explain (i.e. psychosis, dementia)
  - 50% DID NOT; had normal or even above N Iqs
- Suggested term senile breakdown disorder
2nd case series, and a name...

- Drs. A.N. Clark & G.D. Mankikar (Lancet 1975) studied 30 elderly patients admitted to their Geriatric Unit for acute illness & extreme self neglect
  - Pts similar to previous case series, but noted also hoarding behaviors
  - Also high mortality; 48% death rate after admission to acute care
  - Again ~50% had no d_x of dementia or a mental health disorder
- Suggested eponym Diogenes Syndrome
Why Diogenes?

- **Diogenes of Synope** → Greek Philosopher (412-323 BC)
- Scorned and rejected material wealth & possessions
  - “life according to nature”
  - “self-sufficiency”
  - “lack of shame”
  - “contempt for social organization”

*Diogenes, Jean-Léon Gérôme, 1860*
Can I do anything for you, Diogenes?
Can I do anything for you, Diogenes?

Yes, step aside...you are blocking the light.

*Alexander & Diogenes, Nicolas Monsiau 1818*
Diogenes Syndrome (DS): synonyms?

- **Social Breakdown Disorder** (*Macmillan 1966*)
- **Gross Self Neglect syndrome** (*Cybulská 1986*)
- **Senile Squalor Syndrome** (*Shah 1990*)
- **Social Breakdown in the Elderly** (*Ungvari 1991*)
- **Syndrome of Extreme Self-Neglect** (*Refler 1996*)
- **Litter Hoarding Syndrome** (*Jurgens 2000*)
- **Messie-Syndrom** (*Barocka 2004*)
Other eponyms suggested; Havisham’s and Plyushkin’s syndrome)

(Right) Miss Havisham in her rotting & never used wedding dress, in Charles Dickens’ Great Expectations
Diogenes Syndrome: sub-types

**Primary (50-70%)**
- Intentional
- Not related to mental illness

**Secondary (30-50%)**
- Unintentional
- Related to mental illness:
  - Schizophrenia
  - Depression
  - Dementia
  - Alcoholism
NOT quite the same as Elder Abuse*

- Often long pattern of repeated (and stubborn) gross self neglect with refusal for help
- Intense frustration for family, medical, hospital & community resources

* some researchers would argue secondary Diogenes is...
Self Neglect

- Inability to attend to one’s health, hygiene, nutrition or social needs
- Incidence & prevalence increases with age
- Association with: depression, dementia, mental illness, substance abuse, frailty, vision impairments & elder abuse
DS Self Neglect = similar presentation as elder abuse

- Late presentation to medical attention
- Poor/itchy skin, matted hair, infestations (lice, scabies, etc)
- Unexplained bruises, injuries, sacral ulcer
- Poor hygiene (smell), layered/disheveled clothing (“Doctor’s Dress”), neglected teeth/feet

- Dehydration, malnutrition, fecal impaction, incontinence are common with ED presentation
Self Neglect

- Poor nutrition common
- Generally living on tea, toast, bread, biscuits, tins of food
- ETOH (mis)use can be significant
DS=Extreme Self Neglect

- Often biomarkers of protein energy malnutrition:
  - Anemia (Hb <120) 43%
  - Low serum Iron 60%
  - Low serum Folate 50%
  - Low serum Albumin 66%
  - Low urine Ascorbic Acid 100%

Clark et al, Lancet 1975
Domestic Squalor

- people passively or even actively invaded by their rubbish
- worse if low vision, anosmia, mental illness, mobility issues
- often refuse/decline help to clean up
Domestic Squalor

- Infestations are common (i.e. mice, rats, cockroaches, maggots, bed-bugs)
- Repulsive to home care workers; may refuse to enter home/apt. unless pest eradication done
- Associated with ill health and unsafe home situations
Squalor/Hoarding & Fire Hazards

- Fire code violations common
  - Accumulations of combustibles
  - No clear path to exits
  - No working smoke detectors
- May create safety risks to others (i.e. apartment house dwellers)
- Fire Marshal may have to intervene
- May only be found after a fire...
Hoarding

- Hoarding behavior is common among many animals
- ~70 species hoard, mostly food
- Studies in hoarding in rodents have shown that collecting is driven by subcortical frontal lobe structures

Pack rat in *midden* (nest)

Magpie nest woven of metal
Hoarding

- also occurs in humans young and old
- excessive accumulation with failure to discard leading to impaired ADLs
- Associated with OCD (2.5% of general population), and hoarding sub-group ~15% of that
OCD & Hoarding (video)

- Brilliant as young man
- Compulsive hand-washing / OCD
- never worked, disability
- Never let family into home inherited from his mom
- Spring 2006 Hamilton: Police broke in (family hadn’t heard from him in several days); found he had died of CHF
Hoardings:
Association w/o Psychiatric disorders

- Anxiety/OCD
- Depression
- Eating disorders
- Tics/Tourettes
- Addictions
- Autism
- Social phobia
- Schizophrenia
Hoarding in Psychosis

- Elderly man with life long schizophrenia; followed by Hamilton Public Health
- Toronto “remittance man”
- Collecting rubbish found in streets (including life-size cut out of Santa Claus)
- Collecting reduced after restarting atypical neuroleptics
Hoarding: Neurological basis?

- also occurs as a new behavior in brain injury
- ABI patients in this study had damage to the right mesial prefrontal cortex (MPFC) → abnormal hoarding behavior
- ? releasing the primitive ‘hoarding urge’ from normal restraints.

Anderson et al, Brain 2005
81 yo married man with Parkinson’s & CHF
Over last two years suddenly started accumulating tools & fastening supplies; now taking over condo
Bedroom (left) with plastic shelving stuffed with screws and nails next to bed; power tools on floor

Close up of his bedroom wall; note items affixed with duct tape, odd screws, dental floss...
Married couple who hoarded & neglected (*Diogenes au deux*)

- 71 yo man with FTD, wife no formal psych diagnosis
Animal Hoarding

- Hamilton SPCA uncovers ~10 severe cases/year and monitors another dozen or so households annually.
- Common to find dead animals, house strewn with animal wastes.
- Usually middle age or older “owners” living alone.
- Women (usually) hoard cats, men dogs; birds often hoarded too.
Social Withdrawal

- Often become reclusive & social hermits
- Minimal contacts with outside world which is seen as a hostile & uncaring place
- Famous example of the *Collyer Brothers* of 1940s New York City

*Diogenes* by Waterhouse (1882)
Harlem Recluses:
Homer & Langley Collyer
1947: an anonymous phone tip

- "There’s a dead man inside…"
- Took NYC Police 14 hrs to break in
- Called the fire-brigade for ladders to higher levels
- One lone police officer enters; he is gone a long time...
Where’s Langley?

- body of Homer Collyer found seated in a chair ➔ dead only 10 hours
- Sensational US manhunt for the missing brother
Where’s Langley?

- body of Homer Collyer found seated in a chair → dead only 10 hours
- Sensational US manhunt for the missing brother
- Langley found 2 weeks later not 10 feet away, trapped in his own death trap
Aftermath: 180 tons of rubbish

Rat infested Collyer mansion declared unsafe: razed to ground
Utter Lack of Concern

- Poor insights & judgment around self or home
- Flat denial that there is a problem
- Cognitive inflexibility = eerily similar to patients with Fronto-temporal Dementia (Pick’s Disease)
Frontal Lobe Dysfunction

- The **frontal lobes** contain brain structures important for executive functions, such as planning, judgement, regulating behaviour & exercising self-control.

- If damaged, → range of behaviors:
  - i.e. apathy, swearing, undressing, urinating in public, eating & drinking non-food items and so on
FTD: Core diagnostic features

- Insidious onset and gradual progression
- Early decline in social interpersonal conduct
  - ↓ social graces and manners with active antisocial behaviour
- Early impairment in regulation of personal conduct (*gas pedal analogy*)
  - quantitative departure of customary habit, ranging from inertia to over activity; increased talking, aggression and sexuality
- Early emotional blunting
- Early loss of insight

*Neary et al, NEUROLOGY 1998; 51: 1546-1554*
Aetiology of Diogenes Syndrome?

- End stage of a personality disorder?
- Late stage OCD/Hoarding?
- “perfect storm” of reclusive personality, social situation & cognitive impairment?
- Frontal lobe dysfunction/FTD?
- Pre-morbid Personality traits
  - Aloof, suspicious, unfriendly
- Pre-morbid behaviors
  - Hoarding, reclusive, messy
- Personality disorders
  - Schizotypal, Schizoid, OCD

Predisposing risk factors
- Pre-morbid Personality traits
- Pre-morbid behaviors
- Personality disorders

Triggers
- Mental Illness
  - Depression, dementia
- Medical co-morbidities
  - Stroke, CHF, COPD, etc.
- Psycho-Social
  - Isolation, ETOH, retirement, divorce, death of spouse
- Pre-morbid Personality traits
- Pre-morbid behaviors
- Personality disorders

Triggers
- Mental Illness
- Medical co-morbidities
- Psycho-Social

Diogenes phenotype
How is DS identified?

- Often only by chance
  - person collapses, trapped in rubbish, fire, violence, etc.)
- Recurrent visits to hospital for 2’ self neglect
- Often trigger by Public Health
  - issues related to behaviors
    (complaints from neighbors about smell, mice, etc. 2’ filthy living situation)
Suspect DS if:

- Patients filthy, unkempt and malodorous on presentation (usually after a fall or syncope)
- Neglected feet, poor dentition (or no teeth)
- Staff complain of smell of patient/clothing
- Family raise issues of hoarding, self neglect
- $\text{DD}_{x} = \text{elder abuse, mental illness, delirium, Dementia, poverty, & ETOH}$
Demographics

- Male~Females (one study 70% F)
- Can occur in younger patients (i.e. middle aged)
- However much more common in the elderly than younger people
  - Average age 75.6
  - Median age 77 for women & 79 for men
Incidence of Diogenes Syndrome

- NOT RARE
- 5 per 10K adults 60+ in reported cases
  - 10x more common → TB in Western World
- Likely underreported by public health
  - subjects don’t self identify, only found if present to ED or discovered by social services
- ? Relationship with homelessness (diogenes aux via?), or religious hermits? (diogenes aux deus?)
Risk Factors for DS

- Cognitive impairment
- Personality Disorder (OCD/schizotypal)
- Depression
- Elderly/Living alone
- Low income
- Previous hip #
- Previous stroke

Abrams et al, Am. J. Psychiatry, 2002
DS Medical co-morbidity in 50%

Houston Self Neglect Survey (1999-2004; n=538)

- Hypertension 51.6%
- Diabetes 25.2%
- Dementia 29.7%
- Arthritis 20.1%
- Stroke 17.7%
- Depression 14.3%
- CAD 9.4%
- Delirium 7.3%
- COPD 7.0%

Psychiatric diagnoses

- No clear DSM IV diagnosis in 50% of patients
- Other 50% may have recurrent depression, alcoholism anxiety, psychosis, OCD, or cognitive impairment (Dementia)
# Impairments in cognition/function

<table>
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<tr>
<th>Test</th>
<th>65-75 years</th>
<th>75+ years</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>38.0 %</td>
<td>60.5 %</td>
<td>388</td>
</tr>
<tr>
<td>Clock Drawing Test</td>
<td>45.7 %</td>
<td>71.6 %</td>
<td>355</td>
</tr>
<tr>
<td>GDS</td>
<td>20.9 %</td>
<td>11.8 %</td>
<td>341</td>
</tr>
<tr>
<td>CAGE</td>
<td>21.5 %</td>
<td>11.6 %</td>
<td>311</td>
</tr>
<tr>
<td>Functional Activity</td>
<td>59.5 %</td>
<td>83.4 %</td>
<td>314</td>
</tr>
</tbody>
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Table: % of Elderly Self Neglect Patients with abnormal test scores in the Geriatric Assessment Battery, Houston Texas 1999-2004

*Dyer et al Am J. of Public Health, 2007*
Mortality Increased in DS

- In Clark’s case series of DS (n=30); 46% acute care mortality for DS patients who present to acute care (Clark et al 1975)

- 2x risk of death in self-neglecting seniors admitted to nursing homes vs other seniors (Lachs 1998)

- 50% of DS pts are dead in 5 years (Hanon et al 2003)
DS: Falling through the cracks

- Strong refusal of help
- Strong denial there is a problem
- Assessments/Interventions difficult
- Gaps in services and legislation
Ethical & Legal issues

- Do mentally competent persons have the right to neglect themselves?
- Do health authorities have an obligation to intervene?
Society vs individual rights

- Society may protest at their deplorable home situation & lack of conformity but has NO RIGHT to make them move/clean up if competent.

- Care by consent should be the principle in mgt.

Car Lady, Miss Ann Naysmith, 60
Capacity & Competency Issues

- People can be capable & competent & still make seemingly foolish decisions
- To be capable must understand their condition/situation, the choices available, & the pros & cons of each choice
Management of Diogenes
DS curiously overlooked/defined

- Term exists in a Evidence Based vacuum
  - little research attention
  - No standard definition
  - Not a DSM IV or ICD-10 coded diagnosis
- reported in public newspapers more often than in medical journals

- Just a Geriatric curiosity?
- Or possibly new Geriatric Syndrome?
DS as a Geriatric Syndrome

- impairments in many different Bio/Psycho/Social systems typical to aging → typical patterns of decline in function and/or independence

- Example “Geriatric Giants”: cognitive impairment, falls, immobility, incontinence, dizziness, malnutrition

- such syndromes benefit from a comprehensive and multidimensional approach to uncover/treat risk factors

- A similar strategy for Diogenes Syndrome?
Assessment & Management

Multidimensional approach

- Global assessment that includes:
  - Medical & Psychiatric history
  - Medication Listing & what should be on
  - Functional Inquiry (ADLs, mobility, vision, hearing, continence etc.)
  - Social history and current living situation
  - Cognitive Testing
Mgt: You are going to need help

- Get OT to do cognitive testing (next slide)
- Get biomarkers of Protein Energy Malnutrition and involve Dietary
- You want to get SW, and CCAC involved
- If older patient, you may consider referrals to Geriatric Medicine or Geriatric Psychiatry; if younger Psychiatry
Cognitive Testing

- If FTD or ABI, may do surprisingly well on SMMSE
  - Get a MoCA
  - Get Verbal Reasoning Test
  - Do a Frontal Assessment Battery

www.mocatest.org
Management Plan

- You want to stop stop-ables, start start-ables, & improve improve-ables

- Goal is to send the person home if at all possible →

- Only do so if the person is safe & competent to participate in decision making (i.e. no unintentional neglect)
Process may lead to:

- institutionalization if unsafe 2’ mental illness or dementia
- legal intervention
  - Competency determination
  - Public Guardian & Trustee involvement & Capacity Board
    Hearing can occur if pt disagrees
Challenges

- balance between autonomy and beneficence (or legislation vs ethics)
- denial of severity
- capacity on a continuum, with the balance of individual rights with the additional responsibility for and to the community
Harm reduction strategies

Ottawa Case Management model (used in Ontario)

- Long term Social Worker Relationship key
- CBT approach (“life style coach”)
- May take 6+ visits to even mention de-cluttering
- Small changes at first, intense follow up
Worst thing you can do?

INVASION

Patients will:

- Reacquire trash
- Refuse other help or follow up
- Even more hostile & suspicious
- Ruins trust & therapeutic relationships
Another drawback of forced LTCF placement:

- Some US evidence that Diogenes patients do worse if institutionalized against their will.
  
- In one study, 40% die in 13-year follow up.
  
- Elevated risk of death in NH compared to non-neglecting seniors.
  
- (OR= 1.7, CI 1.2-2.5)

Lachs JAMA 1998
Hamilton Gatekeepers

- New local program to decrease number of DS seniors 60+ living in the community without supports
- Train non-traditional referral sources for seniors at risk
- Funnels referrals to a single point of entry

Hamilton Gatekeepers
Hamilton Gatekeepers

- Provide assessment, intervention, case mgt & F/U
- started January 2006
- run by Catholic Family Services (now 3 FTE) and funded by MOHLTC (and you don’t have to be Catholic)

http://www.cfshw.com/senior-programs-gatekeepers.html
Hamilton Gatekeepers

- ~80 referrals last year
  - (example of shed lady)
- 90% do not have a Family MD
- They follow 70% of these clients
- they take referrals from anyone
  - (most recently, the beer delivery man)
- Work closely with Public Health, Seniors Support Officers, CCAC, PMAC
Geriatric Outreach

- Psychiatry & Medicine for the Aged in the Community (PMAC)
  - Hamilton Health Sciences
- Health for Older Adult Program (HOAP)
  - St Joseph's Hospital
Back to the Case of Mr. J
Mr. J. continuing to decline since discharge

- stopped meds & Family MD visits
- eating less, neglecting personal care
- ++ ED visits for weeping leg ulcers & cellulitis
- Memory worse, ditto judgment & insight
PMAC Home Visit (March 2007)

- Home squalid, filth & garbage accumulating
- Rotting food, evidence of mouse/rat infestation
- Burned outlets, furnace plugged in outlet with extension cord
- Pills on sodden floor (that squelched).
- Patient oblivious to it all; “A little mouse poop won’t hurt anyone!”
Home Visit (cont)

- Pt. awake, alert, malodorous, initially cooperative
- N cardiac & respiratory exam, deconditioned
- Legs edematous & marks from scratching with filthy fingernails
- Refused cognitive examination; more and more hostile and belligerent; threw us out of his home
Back to Mr. J

- Grouchily agreed to follow-up visits
- CCAC CM, Wound Care VON
- Declared incapable (but CCAC disagreed, and son reluctant to fight)
- PMAC CM followed with regular home visits (and learned patient was naming his vermin) →

“Jack the Rat…”
Muddled along; fewer visits to ER as ulcers healed
later on and off refused CCAC supports
Eventually readmitted to hospital February 2008 for CHF & pneumonia
deemed incompetent
Died while waiting placement 18 months since hospital discharge; 11 months since our first visit
Diogenes Syndrome:
Key points
Diogenes Syndrome: Key points (1)

- Extreme self neglect
- Domestic squalor
- Excessive hoarding
- Lack of concern / shame re: residential situation
- Social Withdrawal / refusal of all help
DS Key Points (2)

- Most, but not all elderly
- Usually present in crisis
- 50% 5 year mortality
- Often many co-morbid medical & psychiatric diseases
- Dementia, alcoholism & mental health issues common & should be screened for
DS Key Points (3)

- Complicated discharge issues; issues of capacity and self-determination
- Patients often reluctant to cooperate with testing, medication adherence, or follow up
Who else can help?

- Hamilton’s Gatekeepers
- PMAC (if a Family MD)
- Hamilton Public Health, Senior’s Support Officer, COAST & CCAC can all play a part in harm reduction or monitoring strategies
Future Research Questions

- Can DS be discovered & monitored before patients crash?
- Can mortality/morbidity be affected?
- Can a Geriatric Syndrome approach to DS assessment & management help?
- No large scale intervention trials for DS can be found in the medical literature; can one be devised?
- Do patients with $1^o/2^o$ DS have impairments in frontal lobe functioning that can be picked up early with functional neuroimaging?
Thank You!

QUESTIONS? DISCUSSION?

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Geriatric & Internal Medicine