Serious Self Neglect – considerations for protocols

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- The challenges
- What leads to self neglect?
- Mental Capacity
- Effective interventions?
- Learning from SCRs
- Ways forward

Self-neglect: a complex interplay of challenges

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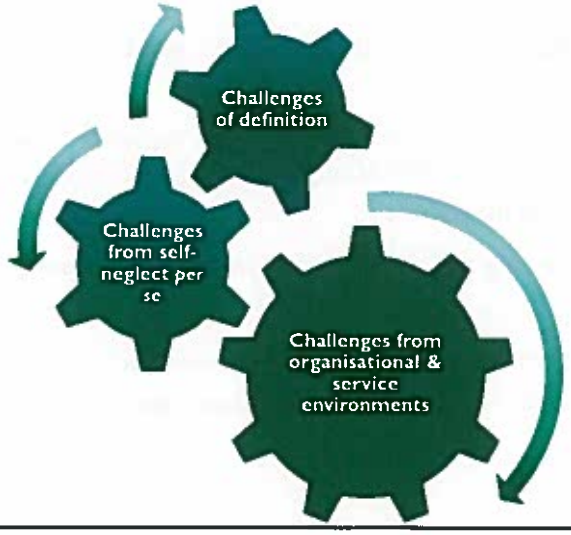


'Policy and legislation alone cannot protect adults who are at risk and living in vulnerable circumstances; there also needs to be commitment at both organisational and practitioner levels to develop decision-making processes that ensure safeguarding and personalisation are interwoven as efficiently and effectively as possible' (Galpin and Hughes, 2011).

Challenges of definition: what do we mean by self-neglect?

No widespread standard definition: a broad range of manifestations

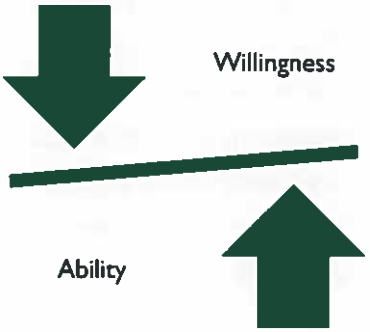
Some have stronger recognition as a 'disorder' (e.g. hoarding to be included in DSM-V independently of OCD, a new name 'hoarding disorder')

Broad working definition, based on the literature

- Lack of self care: personal hygiene, nutrition and hydration, or health
- Lack of care of one's environment: domestic squalor, hoarding
- Refusal of services that might alleviate associated risks

Further complexity in defining and understanding self-neglect

Self-neglect can arise from either inability or unwillingness to care for oneself, or from both unwillingness *and* inability, which are often hard to distinguish from each other



Consequent challenges of finding a framework for intervention

- Self-neglect falls outside current definitions relating to vulnerable adults in England (unlike in the US)
- Self-neglect does not figure within national adult social care eligibility threshold criteria in the same way as 'abuse and neglect' do
- Rarely mentioned in SAB documentation (though SCRs are sometimes conducted when severe harm ensues)
- No fixed pattern of consensus on where responsibility lies: Adult social care? Safeguarding? Health services? Housing?
  = danger that it becomes "nobody's business"
- Need for specific interagency mechanism for information sharing and decision-making

Challenges from self-neglect *per se*

Practitioners talk about:

- complexity of causation, manifestation and intervention
- difficulties of engagement
- tensions between autonomy and duty of care
- assessment of mental capacity
- uncertainty about legal frameworks
- frustration and anxiety
- lack of training

Challenges from organisational & service environments

- eligibility barriers making it difficult to work preventively
- service culture that prioritises independence as a goal and operates care pathways that are not achievable in cases of self-neglect
- workflow patterns based on time-limited care management not longer-term involvement that enable relationship building
- agency cultures and work practices that made interagency and interprofessional negotiations difficult
- finding an organisational home for self-neglect - perceived as everybody's, nobody's or somebody else's business
- different thresholds of concern

Thus a wide range of explanations is offered:

- Self-neglect may be of physical and/or psychiatric aetiology: there is no one set of variables that causes it
- There may be underlying personality disorder, depression, dementia, obsessive-compulsive disorder, trauma response, severe mental distress, and/or neuropsychological impairment
- It may be associated with diminishing social networks and/or economic resources
- Physical and nutritional deterioration is sometimes observed, but is not established as causal
- It may reflect once functional behaviours and personal philosophy (pride in self-sufficiency, sense of connectedness, mistrust)
- It may represent attempts to maintain continuity (preserve and protect self) and control

Mental capacity

- Capacity in the literature is a complex condition
- It involves not only
  - weighing up information and being able to understand consequences of decisions and actions, but also
  - the ability to implement those actions
- Decisional and executive capacity give the real key to assessment

Mental capacity in practice: MCA 2005 guidance

- A person is unable to make a decision if they cannot:
  - understand information about the decision to be made (the Act calls this 'relevant information')
  - retain that information in their mind
  - use or weigh that information as part of the decision-making process, or
  - communicate their decision (by talking, using sign language or any other means).

So: executive capacity?

- Relevant information: could be seen to include information about the consequences of taking or not taking certain action, and the likelihood of those consequences
- Using or weighing information: *(Code of Practice) "Sometimes people can understand information but an impairment or disturbance stops them using it. The impairment of disturbance leads to a person making a specific decision without understanding or using the information they have been given.*
  - *A person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore.*
  - *Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it."*

What we know from practice however…

- Decisional capacity is prioritised in practice
  - The absence of executive capacity may not be taken into account in determining that an individual has capacity
  - Understanding the need to act, and deciding to do so, may be assumed to imply the ability to implement the action
  - Assumption of capacity to make decisions about refusal of intervention may miss the complexity of *'relevant information'* or *'using and weighing information'*
  - Capacity to execute simple functions may mask lack of capacity to sequence decisions in the more complex ways necessary to minimise risk

Effective interventions

- No 'gold standard' evidence in the literature
  - Cleaning may help, but is not by itself effective longer term
  - Assistance with routine daily living tasks can be effective in building trust, ensuring basic standards and mediating risks
  - Early intervention may help prevent entrenched behaviour
  - Debate over effectiveness of SRI (serotonin re-uptake inhibitor) medication for hoarding
  - Promising results (in hoarding) from an approach combining motivational interviewing, organisational & decision-making skills, cognitive therapy, homework to sort & reduce possessions, a focus on harm not symptom reduction (Frost & Steketee)

Approaches prioritised in practice

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- Sensitive and comprehensive assessment
  - mental and physical status, lifestyle, personality traits, social history, activities of daily living, social supports, beliefs
  - Screening tools to assist capacity & risk assessment
- Care by consent – monitoring, negotiation
  - Practical intervention: cleaning, hygiene, healthcare
  - Support to life transitions (return to employment)
- Coercive powers (threat to tenancy, environmental health) provides leverage to secure engagement
- Relationship building to build understanding of the unique experience and trust-based acceptance of intervention

Learning from SCRs

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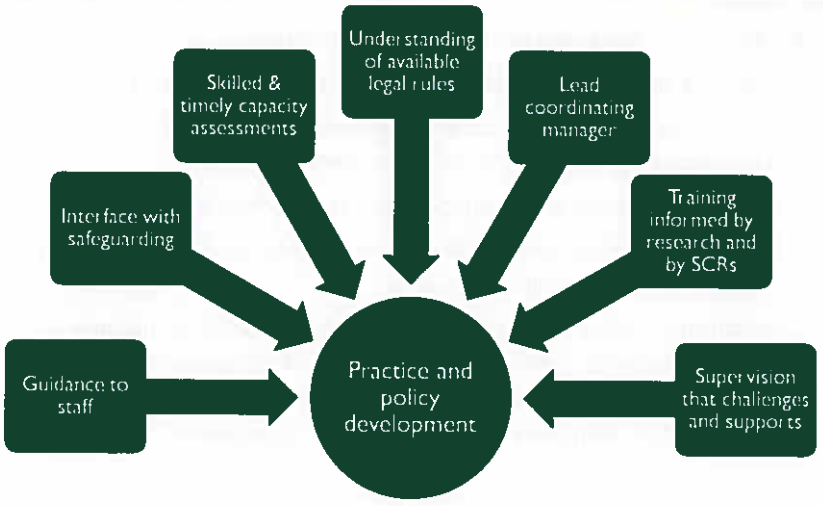


Mental capacity affects perception of risk and intervention focus

Self-neglect challenges professional value positions

- a duty of care, to secure dignity, even where mental capacity is present, is valued and in some cases prioritised over autonomy
- communities are also seen has having rights that counter-balance those of individuals

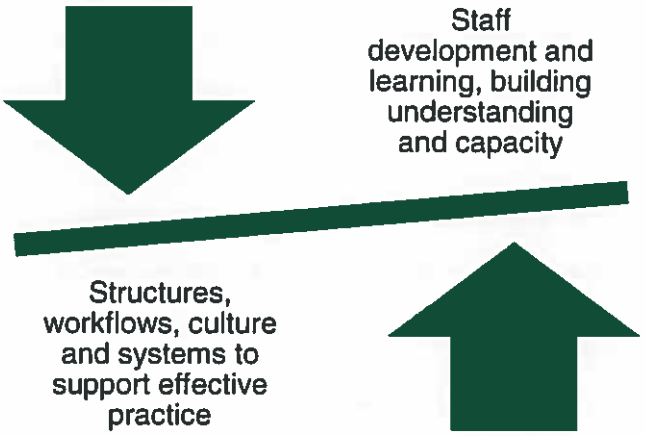
What leads to self-neglect?

- Research has sought to isolate factors that are associated with self neglect:
  - Biological, behavioural, social, environmental
- Whilst correlations have been found, there is no overarching explanatory model
- Complex interplay between mental, physical, social and environmental factors: all important in assessment
- The influence of societal and professional definitions of the 'problem'

What do the perspectives of people who self-neglect tell us?

- Little research done in this area; emerging themes from the scarce literature:
  - Pride in self sufficiency
  - A sense of connectedness to place and possessions
  - A drive to preserve continuity of identity and control
  - Traumatic life histories and events that have had life changing effects
  - In some cases, shame and efforts to hide state of residence from others

Ways forward: *workforce* and *workplace* priorities



Interagency engagement

- Communication & information sharing between agencies
- Discussion of options: what can be done, and by whom
- Identification of whether what could be done should be done
- Risk sharing and shared risk management

Service user highlight:

- Sometimes deep psychological reasons, the result of emotional layers – understand this person
- Self-neglect may be a cause of something and an outcome of something
- History and perspective – practitioners need to understand complex mix of factors
- "Hoarding is my mind." "I need to be needed, hate rejection." "Better than distress from not having something."
- Motivation varies – it can be hard to engage, to trust, to manage the impact on self-esteem
- Some value therapeutic support, some practical help & people who get stuck
- Bullying and coercion unlikely to be effective, encouragement and being motivational & authoritative might
- Listen, demonstrate care, see the needs, be real
- Not necessarily solitary people

Service user highlight - neglect of self care

- Neglect of self care: demotivated by homelessness, health problems, loss, isolation that impacts on self-image & creates negative cognitions
- Different standards: being indifferent to social appearance
- Maintaining some self-care
- Inability to self-care: mental distress, physical ill-health, homelessness

Service user highlight – neglect of environment

Influence of the past: childhood, loss, abuse, bereavement

Positive value of hoarding: emotional comfort, connection to something, "my family", hobby, to be appreciated by others

Beyond their control: voices, obsessions, physical ill-health, lack of space

Service users highlight – willingness to engage

- Already wondering: spot the moments of motivation
- Finding help is difficult: lack of knowledge, accommodation
- No choice (state of home) but directiveness may be seen as pushy & unhelpful
- Right kind of input: not intrusive, gender, amount of therapy, cost, insensitivity versus encouraging, hands-in, person-centred, going the extra mile, reliable, compassionate and understanding
- Timing

Service users highlight – effective interventions

- Support with clearing if sensitive & participatory; care packages that are relevant to perceived needs
- Mental health services, such as CBT or counselling, to tackle deep-rooted issues
- Links with other service users
- Meaningful activity
- Relationship-building: connection, emotional literacy
- Carer support
- Accessing advocacy and resources, such as benefits
- Re-housing
- Information

Practitioners highlight

- Can feel lonely, helpless, frustrating and risky – strong management support and multi-agency collaboration crucial
- Places and spaces to discuss ethical conundrums, such as meaning of consent & duty of care – panels, meetings, case conferences
- Time to build relationships – finding the right person & levers to engage
- Work with neighbours and family too
- Qualities of persistence, patience, resilience, limited expectations, respectful curiosity
- Good understanding of motivational interviewing, capacity and law
- Service development for early intervention
- Small victories important

Managers perspectives

- Complex work so management oversight crucial; clarify balance between autonomy & duty of care
- Supporting staff well-being & knowledge & skill development – meetings, panels, use of experts, protocol development, risk assessment models
- Little data collection so prevalence uncertain
- SCRs and individual agency reviews put self-neglect on the agenda
- If not included in LSAB procedures, where it is owned? Tools and guidance, owned by multi-agency network even if cases worked with through care management teams
- Working together a challenge – threshold bouncing – but removing barriers (integration) brings positive benefits; VARM systems spreading – getting agencies to own the issue
- Concerns about resources and lack of statutory armoury; time & keeping cases open

Research evidence shows a need to develop

Further information & references

- Braye, S., Orr, D. And Preston-Shoot, M. (2011) Self-Neglect and Adult Safeguarding: Findings from Research. London: SCIE. http://www.scie.org.uk/publications/report46.pdf
- Braye, S., Orr, D. and Preston-Shoot, M. (2011) 'Conceptualising and responding to self-neglect: challenges for adult safeguarding', Journal of Adult Protection, 13, 4, 182-193.
- Braye, S., Orr, D. and Preston-Shoot, M. (2013) A Scoping Study of Workforce Development for Self Neglect Work. Leeds: Skills for Care.
- Braye, S., Orr, D. and Preston-Shoot, M. (2014) Self-Neglect Policy and Practice: Building an Evidence-Base. Brighton and Luton: Universities of Sussex and Bedfordshire
- Galpin, D. and Hughes, D. (2011) 'A joined up approach to safeguarding and personalisation: a framework for practice in multi-agency decision-making.' The Journal of Adult Protection 13(3). SCIE Report. London, Social Care Institute for Excellence.