

OUTLINES

A RESEARCH AND EVIDENCE SUMMARY SERIES

An overview of self-neglect

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Background

Self-neglect is one of the key challenges in adult care. Research (Braye, 2015) has identified that health and social care professionals often find self-neglect cases personally and professionally difficult, with ethical and legal considerations, particularly where adults have the mental capacity to refuse support.

While awareness of self-neglect has risen in the past decade, research and evidence is still lacking. The literature has tended to focus on older people and rarely progressed beyond definition and identification, with a noticeable absence of studies on interventions (NIHR, 2021). There is also little recorded in the way of lived-experience.

Definitions

Self-neglect is a complex, multi-dimensional concept first identified in the 1950s. The behaviours are hard to define, measure and address and, as a result, there are many definitions of self-neglect, but no accepted standard. Different policy contexts, service approaches are used nationally and internationally, and it impacts on a wide range of domains (Day, 2016; Lamkin, 2017; Noblet, 2019; Owen, 2022). These variances in conception and operational definitions have likely limited research opportunities.

Gibbons (2006) defined it as “the inability (intentionally or non-intentionally) to maintain a socially and culturally acceptable standard of self-care with the potential for serious consequences to the health and well-being of those who self-neglect and perhaps too to their community”. Most definitions are variations around these themes.

The Scottish Government report ‘Towards a Mentally Flourishing Scotland 2009’ describes self-harm as a response to underlying emotional and psychological distress which can include feeling isolated, having a poor body

image, economic or academic pressures, powerlessness and abuse or trauma.

In England the Care Act (2014) statutory guidance defines self-neglect as ‘covering a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding’.

At its most basic, self-neglect is an inability to care for your basic needs. It can include cumulative, diverse behaviors that threaten self-care, combined with resistance to receiving care from others. It can vary in presentation and severity, and covers a progressive decline in personal, social, physical, mental, and / or environmental domains (Day, 2016; Lamkin, 2017; SCIE, 2018, Pickens, 2021).

Characteristics

Characteristics of self-neglect (HSE, 2014; Lamkin, 2017; SCIE, 2018) can include:

- an inability or unwillingness to manage one’s personal affairs or perform essential tasks, such as dressing or feeding appropriately
- persistent inattention to personal hygiene, health and surroundings
- repeated refusal of services which can be expected to improve quality of life
- lack of self-care through unsafe behaviors leading to physical or emotional harm or pain

Four subtypes of self-neglect have been identified based on work in the elderly population: financial, environmental, global, and physical / medical (Lamkin, 2017).

Issues

The term self-neglect itself suggests the problem is with the individual and does not acknowledge the contextual issues (Day, 2016). Even the idea of self-neglect having common characteristics isn’t agreed on. The term can be

used to describe those unwilling as well as those unable to self-care, some seek to differentiate it from hoarding or squalor, and there are disputes as to whether it is age-related (specifically older people) (Mason, 2020).

Hoarding

Self-neglect and hoarding are often bundled together (or hoarding is seen as a sub-category of self-neglect (Owen, 2022)), but one does not necessarily cause the other (SCIE, 2018). Hoarding disorder has been recognised as a discrete mental health disorder (NIHR, 2021).

Hoarding is the excessive collection and retention of any material to the point that it impedes day to day functioning. Hoarding does not favour a particular gender, age, ethnicity, socio-economic status, or educational / occupational history. Pathological or compulsive hoarding (of inanimate objects, animals, and data) is a specific type of behaviour characterised by:

- acquiring and failing to throw out a large number of items that would appear to hold little or no value and would be considered rubbish by other people
- severe cluttering of the person's home so that it is no longer able to function as a viable living space
- significant distress or impairment of work or social life

Often these attachments can begin with trauma and loss, parental attachment and control issues (Community Care, 2016). Features of hoarding:

- compulsive hoarding may have started as a learnt behaviour or following a significant event such as bereavement
- emotional attachment and distress over parting with possessions, regardless of value or usefulness
- social isolation, typically alienating family and friends, may be embarrassed to have visitors
- people who hoard are typically able to make decisions that are not related to the hoarding

- hoarders typically see nothing wrong with their behaviour and the impact it has on them and others

Who is affected?

Lack of definitional clarity means prevalence studies are inconsistent and few cover the general population (Owen, 2022). But the numbers of adults who self-neglect are increasing, and due to demographics (an ageing population) and underreporting will likely continue to (Pickens, 2021). The Covid-19 pandemic, and the responses to it are also likely to have exacerbated the incidence of self-neglect.

There is no one typical presentation of self-neglect; cases vary in terms of age and household composition (Braye, 2015). Data from general practitioner caseloads in Scotland reported that prevalence rates varied from 166 to 211 per 100,000 populations (Day, 2016).

HSE (2014) identified groups that may present with self-neglecting behaviours, including those with lifelong mental illness; those with degenerative neurocognitive disorders such as dementia or affective disorders such as depression; those who consume large quantities of alcohol; those who live alone, in isolation from social support networks of family, friends and neighbours.

Yu's systematic review (2020) identified higher risk in these characteristics:

- sociodemographic (male, older, lower economic status and educational level, marital status, and lower number of children)
- health (cognitive impairment, lower level of physical function, nutritional status, higher number of medical comorbidities, pain)
- psychological (depression)
- social context (living alone, lower social networks and social engagement, lower neighborhood cohesion, neighborhood disorder)

It may be more prevalent among older people because of bio-psycho-social factors, which can be exacerbated by advancing age and living longer (Owen, 2022), accompanied by an increased incidence of mental health, chronic and degenerative physical illness, isolation and depression.

Though the literature is mostly focused on older people, self-neglect occurs in the younger population and is prevalent in those with mental illness.

Younger people who displayed features of self-neglect generally have fractured chaotic life histories, i.e. alcohol/drug addictions, poor physical function, and health issues (Day, 2016).

People with severe mental health problems often struggle to manage everyday tasks such as hygiene, housework, shopping, cooking, and budgeting. Two recent studies (2013 and 2016) in England identified self-neglect as a common problem among this group (Birken, 2020).

There is little research around interventions to assist personal self-care for people with severe mental health problems, and little guidance for practitioners in how to address these problems (Birken, 2020).

While those with major mental disorders are vulnerable to a range of issues such as homelessness, sexual exploitation, substance and alcohol use disorders, poor social support, a lack of access to health and care services, it is not clear if or how self-neglect contributes to this. For psychiatric patients, self-neglect may be a transient, treatable condition that is a direct result of the decompensation related to a mental illness (Lamkin, 2017).

How does it manifest?

Self-neglect exists as a set of maladaptive behaviours, and an unhealthy behavioral and/or socio-environmental condition. These behaviours (HSE, 2014; Lamkin, 2017; Noblet, 2019) can include:

- poor personal hygiene

- poor diet and nutrition, including obesity and eating disorders
- inappropriate or inadequate clothing, including lack of necessary medical aids
- unsafe home environment and neglecting household maintenance
- hoarding and animal collecting
- refusal of treatment and resources
- non-compliance with medication regime and non-attendance at medical appointments
- refusal to allow other organisations on their property, such as water, gas and electricity providers
- selective mutism
- mismanagement of financial affairs
- social isolation

Consequences and adverse outcomes

Self-neglect is associated with adverse outcomes and multiple comorbidities (Day, 2015; Day, 2016; Dong, 2017; Lamkin, 2017; Day, 2019; Owen, 2022) and can result in:

- deterioration of physical and mental well-being
- increased mortality
- risk of fire, particularly related to hoarding
- falls and trips
- poor housing structures and lack of repairs
- items falling from a height
- nutritional risks
- insanitary conditions
- infection or vermin
- risk to others, including visiting professionals and emergency services

- loss of accommodation and homelessness
- increased use of health-care services, hospice care, hospitalisation, and emergency department visits
- increased risk of subsequent caregiver neglect, financial exploitation and multiple forms of elder abuse

With a rapidly growing older population, organisations and individuals across health and social care (social service agencies, community organisations, health care providers, social workers, legal professionals) must be able to manage an expected increasing number of self-neglect cases (Dong, 2017).

Owen's (2022) study with adult safeguarding managers found the most cited physical health consequences were falls, malnourishment, amputations and ulcers. Several participants referred to the wider environmental impact of self-neglect and hoarding, leading to concern and complaints and police involvement, legal action and anti-social behaviour.

The psychological consequences may include anxiety and depression and a decline in cognitive function and social function. These could, in turn, lead to isolation from family and friends, infestations and fire hazards, which could place both the patient, neighbours and attending health staff at risk (Noblet, 2019)

Causes, predictors, and risk factors

The manifestations and consequences of self-neglect are tangible and visible and easier to recognise. But unlike other kinds of abuse or neglect there is no 'perpetrator' which makes establishing the causes difficult. And with more entrenched behaviour, these causes may be difficult to unearth especially if an individual is themselves unaware of the triggers (Owen, 2022). This makes it difficult to define and develop interventions.

That said, there are multiple attempts at listing or explaining the cause and risk-factors associated with the development of self-neglect, alongside a

general agreement that no one theory can explain it (Day, 2016). The causes, symptoms and consequences are closely related and hard to disentangle so it is not always possible to establish a root cause, or causes (Community Care, 2016; SCIE, 2018; Noblet, 2019; Owen, 2022) but can be a result of:

- physical or mental illness - a brain injury, dementia or other mental disorder
- obsessive compulsive disorder or hoarding disorder
- physical illness which has an effect on abilities, energy levels, attention span, organisational skills or motivation
- reduced motivation as a side effect of medication
- substance misuse and addictions
- traumatic life event or loss
- not recognising the level of self-neglect
- isolation
- poor social support
- poor economic circumstances, poverty and deprivation

Owen's paper (2020) explores the commonalities and differences in adult safeguarding managers' understandings of the causes and consequences of self-neglect and hoarding among older people. Most understood causes as a range of bio-psycho-social factors, including chronic physical conditions, bereavement, and isolation. A minority took a more clinical or psycho-medical perspective, focusing on mental ill-health, or referred to the social construction of norms of cleanliness and tidiness.

In Mason's study (2020) social workers saw self-neglect as an intrinsically complex and multifaceted problem, overlapping with a range of contributory issues. Physical (frailty, mobility problems and poor overall health) and mental health (schizophrenia, dementia, depression, etc.) problems and substance misuse (particularly alcohol) overlap with self-neglect.

Lien (2016) sees self-neglect resulting from interactions between poor social support, functional disability, chronic medical conditions, psychiatric illness,

and mild cognitive impairment, alongside an individual's social, cultural, and environmental circumstances.

Picken's study (2021) in the United States highlighted known predictors (symptoms or indicators present at the time of onset) including: stressful life events, older age, a prior history of a hip fracture or cerebrovascular accident, objective physical function decline, self-reported physical function decline, frail or pre-frail status, male gender, low income, and cognitive decline.

Day (2019) identified physical / psycho-social risks including:

- impaired physical function
- pre-frailty
- pain
- nutrition
- multiple chronic diseases
- autism
- trauma
- alcohol / substance abuse
- living alone, isolation, reduced social networks
- service refusal
- poor self-esteem, coping

Stigma can further reinforce isolation, which has been seen as both a cause and consequence of self-neglect and hoarding behaviours (Owen, 2022).

Physical and mental health

Mental ill-health and physical health problems are cited as primary causes of self-neglect and hoarding (Owen, 2022). Sometimes self-neglect is related to deteriorating health and ability in older age. Diogenes syndrome is a behavioural disorder among older adults manifesting as extreme self-neglect, domestic squalor and a tendency to hoard excessively (Noblet, 2019).

Conditions such as disability, stroke and diabetes are mentioned in relation to reduced mobility and difficulty maintaining cleanliness and hygiene.

Those most at risk may have mental health issues, including depression, PTSD, OCD and dementia (Noblet, 2019; Owen, 2022). There is often an assumption that self-neglecting behaviours indicate a mental health problem but there is no direct correlation (SCIE, 2018).

The ageing global population means increasing numbers of older people suffer from age-associated neurodegenerative diseases, including multiple classes of dementia. When the disease becomes severe, a person's capacity for self-care decreases due to difficulties with memory, processing information, and communication skills. The person's ability to manage a home, food and personal hygiene decreases; at the same time, the person often becomes resistant to receiving care from others (Thelin, 2021). Striking a balance between self-determination and protection is a significant ethical challenge for social workers in dementia care.

Beliefs

People's beliefs and cultural / life views, originating from family norms, a desire to withdraw from society, or preferences for alternative medicines or healing can become entrenched and lead to self-neglect and hoarding behaviours (Owen, 2022). For older people this may include not wanting to complain, fear of professional intervention, fear of losing their home, pets and possessions.

Trauma

Triggering events are often mentioned as prompting self-neglect and, more commonly, hoarding behaviours. Loss, particularly bereavement, was identified as a type of traumatic reaction that could lead to the loss of identity or co-dependent relationship, and therefore the beginning or exacerbation of self-neglect and hoarding (Owen, 2022). Lien's study (2016) of narratives of self-neglect among older people in the US revealed traumatic personal experiences, violent victimization, physical trauma, and sexual abuse, exposure to war or political violence, and prolonged mourning. Five behavior

patterns were also identified: significant financial instability, severe lifelong mental illness, mistrust of people or paranoia, distrust and avoidance of the medical establishment, substance abuse or dependence.

Best practice / interventions

Providing successful interventions to help people who are self-neglecting and hoarding is challenging and there is little supporting evidence of effective interventions. While there are agreed upon areas of best practice these derive more from accumulated practice wisdom than formally evaluated interventions (Owen, 2022).

SCIE (2018) found no single standard intervention. The key themes were flexibility (to fit individual circumstances), negotiation (of what was within the service user's zone of tolerance), balance (between competing imperatives such as risk and safety) and proportionality (to moderate rather than seek to eradicate risk, in a way that preserved respect for autonomy).

Analysis of Safeguarding Adults Reviews in England revealed the importance of good attendance at whole system meetings, effective information sharing, and good knowledge and use of safeguarding and legal pathways (NIHR, 2021). Many assert that coordinated, multi-disciplinary, person-centred interventions are successful in supporting and improving the well-being of older people who self-neglect and hoard (Owen, 2022). NIHR (2021) identifies expertise from practitioners in the following areas: legal and ethical; relational; emotional; knowledge; organisational; and decision-making (NIHR, 2021).

SCIE's research (2014) identified three key sets of factors for effective practice:

- knowing: understanding the person, history, significance of the self-neglect, alongside knowledge resources underpinning practice
- being: showing personal and professional qualities of respect, empathy, honesty, reliability, care, being present, being human

- doing: balancing hands-on / hands-off approaches, seeking the smallest element of latitude for agreement, doing things to make a small difference while negotiating for bigger things, deciding with others when intervention becomes a requirement

Their 2018 reporting includes general pointers for an effective approach, including:

- multi-agency: work with partners to ensure the right approach for each individual
- person-centred: listening to and respecting the views and perspectives of the individual, working towards outcomes they want
- acceptance: good risk management, not behavioural change, may be the best achievable outcome
- analytical: identifying underlying causes to help address the issue
- patience and time: short interventions are unlikely to be successful, practitioners should take a long-term approach
- always go back: regular, encouraging engagement and gentle persistence may help with progress and risk management

Multi-disciplinary / multi-agency approaches

Studies of self-neglect often reflect the diversity of needs, including health (GPs, community nurses, mental health services, substance misuse services, gerontology clinics, paramedics, hospital staff, and allied health practitioners), housing (tenancy support, housing repairs, and landlords), the voluntary and community care sector (care agencies, meals on wheels, day centres, and befriending services), as well as other services such as the police, pest control and the fire services (Mason, 2020). Because of the complex issues involved, multi-agency involvement, collaboration, and shared responsibility is key to support. Whether this is signposting sources of support, utilising local partners such as the RSPCA or fire service (SCIE, 2018), or working as part of a multi-disciplinary team. Local authorities should work with partners to ensure:

- strategic and operational infrastructure, and coordinated interdisciplinary involvement
- agreed policy and guidance that includes clear referral routes and strategy for dispute resolution
- an approach from strategic level to work on the ground, including shared ownership, risk assessment and management
- the Mental Capacity Act is well understood and implemented in context and not used as a justification for inaction
- a clear record is made of interventions, decisions and rationale
- relationship-based working and time for long-term work is supported
- pressure from others (agencies/family/neighbours/media) is managed
- training, supervision and support for staff dealing with people who self-neglect to help them understand the complexities, the possibilities and limitations for intervention

Collaboration was often highly effective on the ground (SCIE, 2018), with examples of strong engagement between adult social care, medical and health practitioners, the police, housing, environmental health, voluntary organisations and others to develop shared understandings that inform the interventions. Case conferences, team discussions, multi-agency risk panels and other ways of convening partners were generally experienced as positive in confirming a sense of direction for individual cases, and in agreeing where the most appropriate focus should be placed, and by whom.

Braye (2015; 2019) emphasises interagency cooperation and information sharing alongside:

- management coordination, support and supervision
- detailed procedural guidance such as referral routes, thresholds, dispute resolution
- skilled and timely capacity assessments
- understanding of legal rules

- network meetings and panels to debate and navigate autonomy, self-determination, duty of care and promotion of dignity
- clarity of each agency's role
- leadership in casework and strategy
- attention to key transition points eg. hospital discharge
- recognition of how professional power, culture and status can influence decision-making

Multi-agency meetings should be used to pool information and assessments of risk and mental capacity, agree a risk management plan, and consider legal options. Outcomes of plans should be reviewed routinely. Information sharing should be comprehensive so that all agencies involved have the full picture. Referrals should be detailed where one agency is requesting the assistance of another to meet a person's needs (Preston-Shoot, 2020).

Relationships

The one theme that emerges from the literature, from interviews with practitioners and people who use services, is the primary intervention being good relationships between practitioners and people who self-neglect. Building trust and negotiation is critical for success (HSE, 2014).

The importance of a person-centred approach is emphasised (Braye, 2015). This comprises proactive rather than reactive engagement, and a detailed exploration of the person's wishes, feelings, views, experiences, needs and desired outcomes. Concerned curiosity is helpful, characterised by gentle persistence, skilled questioning, conveyed empathy and relationship-building skills. Building up a picture of the person's history may help to uncover what is driving and maintaining self-neglect and hoarding (Preston-Shoot, 2020).

Maintenance of contact and continuity is advised so that trust can be established. Relationships take time to build, and sustained involvement over a long period of time may be needed to build the rapport and trust that can achieve tangible outcomes. The people who use services emphasise the

practitioner's ability to show humanity, be reliable, show empathy and patience, be honest and work at the individual's own pace as important components of helping (SCIE, 2014; NIHR, 2021).

Long-term involvement is necessary because people who self-neglect and hoard are frequently and repeatedly referred to services. This long-term support can be difficult for managers to justify when, given the complex nature of the behaviours, outcomes seldom restore the person to a pre-existing or normative state of well-being (Owen, 2022).

The literature suggests that more concrete interventions work better if they take place against the backdrop of these trusting relationships (NIHR, 2021). Relationships should be built around empathy, trust, reassurance, respect, and being non-judgemental. Care by consent is preferable, with relationship building tuned to individual experiences (Braye, 2015).

According to SCIE (2018) practitioners have to rely on negotiation. Consensus and persuasion respects a person's autonomy and seeks to avoid alienation where intrusion is likely to be resented, for example some may be upset or traumatised by interventions like deep cleaning. When developing an approach it is important to try to understand the individual and what is driving their behaviour.

Approaches that enable the practitioner to explore and understand the individual's life history, and its possible connections with current patterns of self-neglect, are important. SCIEs (2014) report showed early experience, trauma, loss and relationship figure strongly. Practitioners recount a better experience with bespoke interventions that respond to and account for the individual's life experience, networks, relationships and motivations.

Other areas highlighted (Braye, 2019; Research In Practice, 2019) for effective practice include:

- focus on family interactions
- continuity of involvement and persistence

- being able to spot moments and motivations where change might be possible
- open communication about risk and interventions, particularly where coercive action is a possibility

Where there are difficulties in engagement and cooperation, generalised assumptions should be avoided and each person's history, level of risk and mental capacity accounted for. Practitioners should explore termination of contact, looking at the adequacy of personal information, the effects of biography, chronology, history and context on the decision, or possible undue influence by others (Braye, 2015; Preston-Shoot, 2020).

Assumptions about lifestyle choice, attitudes or pre-judgement regarding misuse of drugs and alcohol, can result in the meaning behind patterns of behaviour being lost, and an under-estimation of the impact of trauma on self-neglect (Preston-Shoot, 2020).

Organisational

The importance of creating a strategic and operational infrastructure for self-neglect practice is highlighted. Facilitators of good practice can be seen at an organisational level with recommendations around robust policies, protocols, tools and systems for supervision and staff support across the agencies involved, including guidance that sets out expectations of managers in overseeing self-neglect work (Braye, 2015). In complex cases real-time management of risk in working with people who refuse services and their inclusion on the agenda of risk panels is recommended. Managers in particular emphasised the importance of inter-agency governance (SCIE, 2014). Moving away from eligibility-based, care management approaches towards adoption of person-centred and relationship-based principles is central to this.

Effective practice is best supported organisationally (SCIE, 2014; Braye, 2019; NIHR, 2021) when:

- strategic responsibility sits clearly within a shared interagency governance arrangement
- agencies share definitions and understandings of self-neglect
- interagency coordination and shared risk-management is facilitated by clear referral pathways, communication and decision-making systems
- longer-term supportive, relationship-based involvement is accepted as a pattern of work
- multi-agency workforce development, training and supervision supports the issues, challenges, skills and emotions involved
- there is accessible staff guidance, support and supervision
- expectations are recorded and audited
- a culture of challenge and escalation exists within the organisation
- legal literacy is developed and supported and legal options are explicitly considered

Referral pathways are another aspect of infrastructure that would enable effective responses. Managers were keen to develop ways of capturing data on self-neglect referrals and outcomes, while recognising the challenges of defining it, agreeing thresholds, and securing participation from all agencies involved (SCIE, 2014).

Assessment and capacity

For patients with severe forms of self-neglect, providers should assess the patient's capacity to make appropriate decisions regarding their care, and should intervene if the patient is at elevated risk for harming themselves or others (Lamkin, 2017). A comprehensive assessment is essential that assists practitioners in identifying, assessing, and monitoring capabilities and risk. It is essential that a capacity assessment is made early on and reviewed as necessary (SCIE, 2018).

Capacity

Knowledge of legal frameworks for intervention, either when the individual lacks capacity, or where expressed wishes are overridden, is an essential underpinning to practice. Involving mental health and mental capacity, human rights and information sharing, public health and social care, the legislation can be complex. In SCIEs report (2014) mental capacity frequently featured in practitioners' narratives, and was also recognised as a key determinant of what intervention could and should take place.

Braye's (2015) study of serious case reviews where self-neglect featured, showed mental capacity as a crucial issue, including levels of knowledge of legislation and procedures, and the thoroughness with which assessments are completed and reviewed. Recommendations include the need to provide guidance for staff, and recording of capacity at the point of service refusal. Such work may require practitioners to challenge their own assumptions about lifestyle choice and capacity, and the statutory assumptions of capacity and autonomy.

Assessments

Dong (2017) and Noblet (2019) identify the need for a more comprehensive multi-agency evaluation combining clinical assessments and psychological, social, behavioral, environmental, and cultural evaluations of an individual once self-neglect has been identified. These assessments can be used to determine the assistance required, and prioritise needs and available resources. A multidisciplinary approach is required across all environments. Nurses may be best placed to observe the multiple conditions - nutrition, hydration, injuries, frailty - indicating self-neglect.

HSE (2014) breaks down the process of preliminary assessment on self-neglect:

- establish whether the vulnerable person is aware of the referral and what their response is

- consult with other health and care professionals in order to gain further information, focused on establishing the areas of concern
- establish if there have been any previous attempts to intervene and what the outcomes were
- arrange for an appropriate person to meet the individual to get their views and wishes
- arrange a multidisciplinary strategy meeting, where a decision can be reached as to the person best placed to take a lead role.

Relationships and professional judgement remain a valued and effective means of conducting assessment, including interviewing technique, cultural expectations, individual personality characteristics, establishing if self-neglect is active or passive, and gaining information on recent and past life story (Day, 2016). Assessment of capacity does not negate the duty to act for an individual's wellbeing and there should be a balance between respect for autonomy and this.

Assessment requires time to address the impact of adverse experiences, including issues of loss and trauma. It also should explore repetitive patterns. Comprehensive risk assessments are required, especially in situations of service refusal. Thorough mental capacity assessments are also advised, which include understanding and consideration of executive capacity, recognising that a person's articulation, skills and good cognition might mask difficulties (Preston-Shoot, 2020).

Braye (2015) identified a focus on the quality of assessments, care planning and reviews. This includes the importance of follow-up and feedback to referrers, the development of standards for assessment and planning, and continuity of personnel through reassessment and reviews of action plans over time. Assessments should consider and document the relevance of mental health and mental capacity legislation, carers needs and circumstances, and any other legal options.

Care plans

Care plans should be thorough and reviewed regularly. Transitions, hospital discharge and discharge summaries, placement commissioning, and arrangements for mental health treatment, require particular attention and multi-disciplinary involvement (Preston-Shoot, 2020).

Interventions

Specialist treatment can reduce symptoms and risks associated with self-neglect and hoarding, but they are generally modest and behaviours may remain in the clinical range after clinical treatment.

Enforcement

Resorting to enforcement action should be a last resort. There are some options that can be used in extreme circumstances, but often the threat of enforcement can encourage an individual to accept help and support. Levers may include housing enforcement options based on tenancy or leasehold breaches, and environmental health enforcement based on a public health risk. Local authorities also have powers relating to anti-social behaviour that may be relevant in some cases (SCIE, 2018).

At the severe end of the spectrum public safety concerns add to a justification to hospitalise and to treat (Lamkin, 2017).

Primary Care

NIHR (2021) also identified from the US and Republic of Ireland reports of intensive outpatient primary care programmes, with a multi-disciplinary team (including social workers, senior clinicians and others) focused on self-neglect among older people.

Timed intervention model

Anka (2017) highlighted a timed intervention model of practice set up by an English local authority. This comprised up to 24 weeks of intensive meetings

to prevent and delay the need for care and support. There was evidence of social workers using strengths, relationship-based, and outcomes-focused approaches. The techniques used to engage, achieve change and assess effectiveness varied, and included the use of photographs to enable the service user to map and assess their own progress over time. The service users valued the time the social workers spent with them and being treated with sensitivity and respect.

Therapy

Some individuals may be helped by counselling or other therapies. Cognitive behaviour therapy, for example, may help people with obsessive compulsive disorder, hoarding, and addictions (SCIE, 2108).

Birken (2020) highlighted a group psychosocial rehabilitation education programme conducted in an inpatient setting, focussing on social functioning, community living skills, and self-maintenance, and included modules on showering/bathing, hand and nail care, dental hygiene, hair care, shaving and toileting. The evaluated intervention was reported to improve self-care, but was assessed as having a serious risk of bias.

As was a one-on-one cognitive adaptation training intervention. It used individualised environmental supports to compensate for the cognitive impairments associated with severe mental health problems that impact negatively on functioning. These included signs and checklists, personal care supplies and simple storage systems to help the person organise their belongings. These supports aim to prompt and facilitate personal self-care and engagement in community-based activities.

Tools and resources

Effort has been made to develop tools but no rigorous evaluations have been conducted.

Qian (2021) identifies eight instruments available to assess self-neglect of older adults, though the self-assessment and proxy reporting usually required is problematic.

A resource from Research In Practice (2020) aims to support adult social care practice with people who self-neglect and lack of care of the domestic environment. The tool is supported by a webinar, which brings together research evidence and provides additional resources to support practitioners working in this area, including:

- an overview of research findings on self-neglect.
- guidance on understanding and engaging with self-neglect
- guidance on practice approaches to support positive outcomes
- an overview of the legal framework for self-neglect practice
- an outline of the key organisational features to support practice
- a practice model illustrating key practitioner decisions
- signposting to research findings and further resources

Camden's Multi-Agency Self-Neglect Toolkit (2020) covers

- an overview of self-neglect
- positive engagement and best practice
- information sharing
- a directory of services
- risk and assessment tools

Barriers and challenges

Supporting people who self-neglect or show hoarding behaviours may be professionally and personally challenging (SCIE, 2018; Owen, 2022).

Historically, self-neglect has differed from other forms of abuse because it does not involve a perpetrator, which has meant a struggle for a clear definition and it being viewed differently from other types of abuse, neglect or exploitation.

Self-neglect is often not just a personal preference or a behavioural idiosyncrasy, but a spectrum of behaviours associated with increased morbidity, mortality and impairments in activities of daily living (HSE, 2014). It's complexity - no overarching explanatory model, the interplay of physical, mental, social, personal and environmental factors, the difficulty in distinguishing between passive and active self-neglect, the need for definition, shared language and context - combined with inadequate knowledge and awareness of self-neglect means there is little research to understand how a range of factors might lead to behaviours that lead to self-neglect.

In real life this results in limited interventions, supporting resources and systems, lack of joined up systems and standardised protocols, and insufficient training for the workforce (NIHR, 2021). Many practitioners are left struggling with cases, feeling alone and isolated (Community Care, 2016).

Other factors that may lead to self-neglect being overlooked:

- the perception it this is a lifestyle choice
- poor multi-agency working and lack of information sharing
- lack of engagement / challenging behaviour from individuals or family
- a desensitisation around repeated cases
- individuals with chaotic lifestyles and multiple or competing needs
- inconsistency in responsibilities across agencies and teams
- lack of legal literacy

Work patterns and resources don't support long-term, relationship-based work. Adult safeguarding managers in Owen's (2020) study identified the problem of late presentation in understanding the causes of self-neglect and hoarding. By the time these behaviours are brought to services attention crisis response is all that can be offered. Earlier help and identification of emerging problems may improve responses. Day (2015) recognises the key role community nurses have in identification of vulnerable adults and people at risk of self-neglect.

All of this is made more difficult by a lack of evidence and limited screening and detection tools, most of which have not been tested for reliability and validity (Dong, 2017).

Organisational issues and cooperative working

Competence of professionals and multidisciplinary team working are also critical considerations (Day, 2016). Contrasting attitudes, and differing approaches and understandings of self-neglect can lead to challenges in working together. Reviews in England raise questions about the quality of cooperative working and point to problems of silo working, poor service coordination, role confusion and poor inter-disciplinary communication (Braye 2015; Mason, 2020).

Social workers spoke about the poor knowledge, different thresholds, value bases, and approaches of other services - social work roles being supportive and relationship based, the police and housing taking punitive approaches, and health and paramedics having episodic contact (Mason, 2020).

From Owen's paper (2022), agencies other than social work should be encouraged to provide more early help to people at risk of developing harmful self-neglect and hoarding behaviours, and that sustained engagement with those affected could help to understand some of the causes and enable effective support and interventions.

SCIE (2014) identified challenges in who takes lead responsibility, who should be involved, and where responsibility resides.

It is rare that a total transformation will take place and positive change should be seen as a long-term, incremental process (SCIE, 2018). There was recognition that care management systems did not always allow the time and continuity of involvement to support relationship-based practice.

Declining help / disengagement

A continuing challenge in addressing self-neglect behaviours is resistance to care and support, and the difficulties professionals face when trying to get self-neglecting people to accept help (Touza, 2019). This can lead to criticism of services who are not perceived to be providing support (SCIE, 2018).

Harris (2021) offers some insight into this, with social workers identifying senior managers and panels requiring engagement, but not understanding that they are self-neglecting and might not engage:

“One of the biggest gripes that I had is constantly having to repeat yourself, tell your story over and over. You disengage and they close the books because you haven’t turned up, so then they do the whole process again, and how much does that cost? I’m back and you want me to jump through this hoop again. There’s doesn’t appear to be a grownup approach that says actually this person is in chaos and therefore we need to adapt our services to be more responsive, more holistic.”

Autonomy and duty of care

There are limitations to what can be done when a person has mental capacity to make their own decisions about how they live but refuses help, and finding a balance between respecting autonomy and fulfilling a duty to protect health and wellbeing is a frequently highlighted challenge (SCIE, 2014; Dong, 2017). The circumstances in which the medical community, family, and society should be allowed to override the will of an individual is a key legal and ethical dilemma in self-neglect management (NIHR, 2021; Owen, 2022).

Braye (2019) asks, is it really autonomy when you don’t see how things could be different; you don’t think you’re worth anything different; you didn’t choose to live this way, but adapted gradually to circumstances; your mental ill-health makes self-motivation difficult; executive brain function is impaired.

If the person does not have capacity, then a decision in their best interests may be made, but it is essential both to take into account the person's wishes and feelings and to enable and encourage their participation (Research In Practice, 2019).

Lived experience

There is little recorded lived experience to provide the perspective of people who self neglect. Braye (2019) provided some insight on the neglect of self-care, including negative self-image and demotivation:

“I got it into my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.”

“I’m drinking, I’m not washing; I wouldn’t say I’m losing the will to live, that’s a bit strong, but I don’t care, I just don’t care.”

“I wouldn’t say I let my standards slip; I didn’t have much standards to start with.”

“(It) makes me tired... I get tired because daily routines are exhausting me, to do the simple things like get washed, put on clean clothes, wash my hair.”

“I always neglected my own feelings for instance, and I didn’t address them, didn’t look at them in fact, I thought ‘no, no, my feelings don’t come into it’”

And the neglect of domestic environment, including the influence of the past, childhood and loss, the positive value of hoarding:

“The only way I kept toys was hiding them.”

“When I was a little boy, the war had just started; everything had a value to me... everything in my eyes then, and indeed now, has potential use.”

“I want things that belonged to people so that they have a connection to me.”

“I don’t have time to make a note of everything in the paper that has an interest to me and so I’m very fearful of throwing something away. The distress of not collecting is more than the distress of doing it.”

And around the concept of lifestyle choice, including assuming capacity and respecting autonomy:

“Well I don’t know to be honest. Suddenly one day you think, ‘What am I doing here?’”

“I got it into my head that I’m unimportant, so it doesn’t matter what I look like or what I smell like.”

“I used to wake up in the morning and cry when I saw the sheer overwhelming state... My war experience in Eastern Europe was scary, but nothing compared to what I was experiencing here.”

“Your esteem, everything about you, you lose your way... so now you’re demeaning yourself as the person you knew you were.”

Future research

There is a need for a conceptual / behavioural framework and standardised definition of what self-neglect is, which could provide a clearer directional plan for assessment and intervention, and allow comparisons of study results across disciplines. These can be used in clinical and community settings to support health care professionals in identifying severe self-neglect, and possibly preventing an early death or changing the behaviours. Current knowledge is based on studies of individuals already in a state of severe neglect. Collaboration among different disciplines is needed to intervene earlier to arrest or reverse the progression of self-neglect (Lamkin, 2017; Pickens, 2021).

A better understanding - through detailed training and guidance - around the range of causes of self-neglect and hoarding by senior staff and managers (as well as frontline colleagues) may improve effective assessment, engagement, risk management and intervention, and could support prevention and better outcomes (Owen, 2022).

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Search Strategy

This summary provides an overview of self-neglect focussing mainly on Scotland and the UK, looking at definitions, possible causes, how it manifests, areas of good practice and the barriers and enablers to this. It was written to support an Adult Protection Committee thematic review of self-neglect. The search was widened to include evidence from the other UK nations and comparable countries from around the world. The date range was limited to 2014-present. There were no limits on study design but did have a focus on currency and accessibility. We used a variety of sources and databases in researching this topic, including NHS National Education for Scotland's Knowledge Network, Social Care Institute for Excellence, Google Scholar, ASSIA, CINAHL, ClinicalKey, Cochrane Library, EMBASE, Emerald, Ovid Databases, ProQuest Public Health. The keywords searched were self-neglect, self-care, adult safeguarding, hoarding, best practice, interventions, and lived experience. As the search developed this expanded to include multi-disciplinary teams, assessment, models and framework.

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