*British Journal of Social Work (2012)* **42**, 725–743
doi:10.1093/bjsw/bcr082
Advance Access publication June 15, 2011

# Professional Social Workers' Views on Self-Neglect: An Exploratory Study

Mary Rose Day*, Geraldine McCarthy, and Patricia Leahy-Warren

*Mary Rose Day, MA HDip PHN, BSc. Dip Mang, RPHN, RM RGN, is College Lecturer and DNP student in the Catherine McAuley School of Nursing and Midwifery, Brookfield Health Science Complex, University College Cork, Ireland, and her research is focused on self-neglect, life-story work, discharge planning and family carers, particularly in the context of older adults and community. Geraldine McCarthy, Ph.D., MSN, MEd, Dip Nursing, RNT, RGN, is Professor and Dean of the Catherine McAuley School of Nursing and Midwifery, Brookfield Health Science Complex, University College Cork, Ireland. She leads the Health Ageing Research theme in the School and her research interests include those associated with chronic disease and self-care. Dr Patricia Leahy-Warren, Ph.D., MSc (research), HDip PHN, BSc, RPHN, RM, RGN, is Senior Lecturer in the Catherine McAuley School of Nursing and Midwifery, Brookfield Health Science Complex, University College Cork, Ireland. She leads the Maternal and Infant Health Research Team within the School and her research interests are focused on such areas as maternal care, post-natal depression, social support, maternal parental self-efficacy, breastfeeding, kangaroo care and public health.*

*Correspondence to Mary Rose Day, Brookfield Health Science Complex, University College Cork, Ireland. E-mail: *mr.day@ucc.ie*

## Abstract

Self-neglect is characterised by an inability to meet one's own basic needs and can be intentional or unintentional. Ageing populations, chronic illness, disability and poverty place individuals at risk for self-neglect. Self-neglect accounted for one-fifth of referrals received by the Elder Abuse Services (EAS) in 2008 in Ireland. Self-neglect (SN) can occur across the lifespan and is a serious public health issue and a social problem that is difficult to detect and diagnose. This article reports findings from a qualitative exploratory study, which explored the views and experience of a purposeful sample of seven Senior Case Workers (SCWs), working in Elder Abuse Services (EAS) on SN in Ireland. Individual interviews were tape recorded, transcribed and thematically analysed. Four major themes emerged from the findings: self-neglect as an entity, assessment, interventions and ethical challenges. SCWs are challenged and frustrated by this complex multidimensional phenomenon. Furthermore, poor operational definitions of 'exceptional circumstances' and 'self-neglect' can lead to diversity in choosing and responding to self-neglect. Suggestions are made about ways in which practice, policy and research can be developed.

**Keywords:** Elder Abuse Services, self-neglect, senior case workers

*Accepted: May 2011*

## Introduction

In Ireland, the Health Service Executive (HSE) is responsible for the provision of healthcare to 4,239,848 people (Central Statistics Office (CSO), 2006) and there are four regions nationally (South, West, Dublin Mid Leinster and Dublin North East). Ireland has an ageing population and, currently, figures for people aged sixty-five years and over are 467,900, or 11 per cent of the total population (CSO, 2006). Aging populations and multiple co-morbidities will increase vulnerability and risk for self-neglect (SN), which is more common in older people (Pavlou and Lachs, 2006). SN is a serious public health issue and a social problem that can occur across the lifespan (Lauder *et al.*, 2009). The concept of SN is complex and poorly conceptualised. There is no standardised national or international definition of SN (Ballard, 2010; Gibbons, 2009; Naik *et al.*, 2008; McDermott, 2010). Perceptions of SN can vary widely across professional groups (nurses, general practitioners (GPs) and social workers (SWs)), cultures and communities (Lauder, 1999*b*; San Filippo *et al.*, 2007). Older adults identified as self-neglecting by professionals engage in a diverse range of self-protecting behaviours in trying to maintain control and preserve identity (Bozinovski, 2000; Kutame, 2007). A number of older adults who SN had no problems with their personal and living circumstances (Bozinovski, 2000; Day *et al.*, 2009; Kutame, 2007). Some view their home as being clean (Dick, 2006) and environmental chaos has been linked to the complexity of the lives of people who SN (Smith, 2001). Thus, SN can present significant challenges for health and social care services (Day, 2010; Scourfield, 2010).

There are no empirical data on the prevalence of SN in Europe or the USA. SN is currently the most common referral received by Adult Protective Services (APS) in the USA. The incidence rates reported to APS range from 37 per cent (Teaster *et al.*, 2006) to 65 per cent of all elder abuse and neglect cases (Dyer and Goins, 2000). In the UK, the estimated incidence is 0.05 per cent per 1,000 in a population of over sixty years (Reyes-Ortiz, 2001). Consultations to primary care services in Scotland (2007–08) identified 166 patients per 100,000 in population with a diverse range of SN diagnosis (Information and Statistics Division, 2009). The majority of referrals to Elder Abuse Services (EAS) in Ireland are classified as SN (20–25 per cent) (Health Service Executive (HSE), 2009). In 2009, 435 cases referred to EAS nationally were classified as SN and 236 (54 per cent) cases came from one of four HSE areas, suggesting difficulties in detection of cases (HSE, 2009).

Historically, the medical literature has dominated the construction of SN (Lauder, 1999*a*). Macmillan and Shaw (1966) were the first to describe SN as senile breakdown syndrome. Since then, many other terms have been proposed to describe SN, such as diogenes syndrome (Clark *et al.*, 1975), social breakdown syndrome (Gruenberg, 1967) and messy house syndrome (Barocka *et al.*, 2004). It has been suggested that the term 'self-abuse' would more aptly describe severe SN (Reyes-Ortiz, 2001).

Some researchers view SN as a distinct syndrome (Naik *et al.*, 2008; Pavlou and Lachs, 2006; Esposito *et al.*, 2006) while others believe it to be a number of symptoms that can be linked to mental and cognitive disorders (Abrams *et al.*, 2002; Halliday *et al.*, 2000). SN is also viewed as a socially constructed phenomenon based on a series of social judgements (Lauder *et al.*, 2002). SN is multifaceted and can encompass physical, psychological, behavioural, societal and environmental factors. It can be accompanied by old age, chronic illness (Dong *et al.*, 2009), mental health issues, cognitive impairment (Halliday *et al.*, 2000), decreased social networks (Burnett *et al.*, 2006), alcohol abuse, clutter, bereavement (Thibault, 2007) and abuse or exploitation (Mosqueda *et al.*, 2008). It can be a lifestyle choice and stressors or negative events can predispose people to SN (Badr *et al.*, 2005; Thibault, 2007) and increase risk for elder abuse (Connolly, 2008).

APS workers conceptualise that people who SN put their health and safety at risk when they do not adequately provide for themselves (Bohl, 2010; Dyer *et al.*, 2005*a*, 2005*b*). Nurses viewed self-care as an important factor in the social construction of SN (Lauder *et al.*, 2001). According to Gibbons *et al.* (2006), self-care theory offers only some explanation for SN and Paveza *et al.* (2008) suggested using a risk and vulnerability model to broaden understanding and context of SN. A conceptual model for SN found that physical and personal living circumstances and mental health are important indicators of SN (Iris *et al.*, 2009). Older adults who SN are challenged by a multiplicity of factors and self-care decisions can be influenced by personal coping skills, culture, beliefs and values of life and death (Gibbons, 2009). SN severity is linked to mortality and risk of death is considerably higher in the first year following identification by APS (Gill, 2009; Dong *et al.*, 2009).

There is no standardised national or international definition of SN (Dyer *et al.*, 2005*a*; Payne and Gainey, 2005). SN has been defined as:

> . . . the inability (intentional or non intentional) to maintain socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well being of the self-neglecters and perhaps even to their community (Gibbons *et al.*, 2006, p. 16).

This definition demonstrates the negative impact of SN for the individual, their family and community. The characteristics and behaviours used to describe individual cases of SN can present along a continuum of severity and have singular or multifaceted elements. These can relate to poor self-

care, poor nutrition, non-compliance with prescribed medication or health care, neglected and dilapidated environments, hoarding of rubbish and having a large number of pets (Gunstone, 2003; McDermott *et al.*, 2009; Reyes-Ortiz, 2001; Smith *et al.*, 2006). Day (2010) described self-neglect as:

> . . . ranging from failure to attend to self-care; leaving bills unattended, non-compliance with treatment regimes, not eating or drinking, service refusal with evidence of SN; to dilapidated homes and environments, faulty electrics, hoarding of rubbish, squalor and hoarding of animals (Day, 2010, p. 74).

SN is not included in the definition of elder abuse in Ireland, UK, Europe or Australia and is not mandated for reporting purposes (Department of Health, 2000; McDermott, 2009; Working Party on Elder Abuse, 2002). This differs from the USA, where self-neglect is included in the definition of elder abuse in a number of states and considered as an aspect of elder abuse by the National Centre on Elder Abuse and the National Adult Protective Services (Teaster *et al.*, 2006).

EAS in Ireland were established with the appointment of thirty-two Senior Case Workers (SCWs) who are Senior Social Workers in 2007 (O'Dwyer and O'Neill, 2008). Procedural policy documents have identified the role of the SCWs in cases in which there are extreme levels of SN or in which older people are seriously neglecting their own care and welfare and putting themselves or others at serious risk (HSE, 2009). SN cases may only come to the attention of services when people are older and at a chronic stage. Referrals can come as a concern from a wide variety of health and social care professionals (health services, hospitals, day-care, sheltered housing and voluntary organisations), legal profession, postmen, police and neighbours. Public health nurses (PHNs) in Ireland who have access to clients' homes are a major source of referrals to SCWs, EAS and play a major role in the ongoing support and maintenance of SN clients in the community (Day *et al.*, 2009, 2012; HSE, 2005, 2009; Hurley *et al.*, 1997, 2000).

A multidimensional approach and a holistic home assessment, building relationships and trust using a multidisciplinary and interagency approach are critical (HSE, 2009; Lauder *et al.*, 2005). Assessment domains include: personal needs and hygiene; home environment; activities for independent living; medical self-care; and financial affairs (Naik *et al.*, 2008).

A number of instruments can be used to support assessment such as the Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975), Clock Drawing Test (CDT) (Critchley, 1953), Bill Paying Test (Sherman, 2008), Geriatric Depression Scale (GDS) (Brink *et al.*, 1982), alcoholism CAGE questionnaire (Ewing, 1984) and the Kohlman Evaluation of Living Skills (KELS) (Kohlman-Thomson, 1992; Pickens *et al.*, 2007). A number of tools have been developed to describe SN: Self-Neglect Severity Scale (Mosqueda *et al.*, 2008) in the USA and the Environmental Cleanliness

and Clutter Scale in Australia (Halliday and Snowdon, 2009). Professional judgements, actions and interventions (McDermott, 2010) will be influenced by assessment of risks and capacity of people who SN, in relation to making and executing decisions (Naik *et al.*, 2008; Skelton *et al.*, 2010). Respecting dignity, self-determination, beneficence, non-maleficence and rights of individuals can present an array of complex ethical and legal challenges for multidisciplinary team members (Day, 2010; McDermott *et al.*, 2009; Scourfield, 2010).

There is a paucity of research critically examining the concept of SN and there are no empirical data on the prevalence of SN in Europe or the USA. There are a number of factors why this paucity persists. These include access to people who SN, ethical challenges and lack of a standardised definition. Research needs to investigate influences of life course, age, family dynamics, neighbourhood characteristics and social determinants on SN (Dick, 2006; Paveza *et al.*, 2008). Few studies have explored the personal perspectives of people who SN (Kutame, 2007; Bozinovski, 2000; Day *et al.*, 2009, 2012) and further research needs to include perspectives of people who SN (Lauder *et al.*, 2009; McDermott, 2009). Future research needs to develop and validate assessment tools for home assessment use (Naik *et al.*, 2008). Exploring the views of the multidisciplinary team members is critical to the prevention and management of SN. Thus, a qualitative exploratory approach examining the experiences of SCWs, EAS who are acknowledged as the first source of SN referrals in Ireland is the purpose of this study.

## Methods

### Research design

The aim of the study was to explore the views and experiences of SCWs on SN in Ireland; therefore, a qualitative descriptive design was used. A qualitative descriptive design was the method of choice as straight description of the phenomena of SN from the SCW perspective was desired (Sandelowski, 2000). Qualitative descriptive designs have been described as an eclectic well-considered combination of sampling, data collection, analysis and pre-presentational techniques. By using this design, the focus is on descriptive validity, which is a comprehensive account of phenomena that both the researchers and participants would agree is accurate (Sandelowski, 2000).

### Sample

A purposeful sample of SCWs, EAS working with people who SN were invited to participate in the research. The total population of SCWs is

thirty-two; however, not all SCWs have clients who SN within their caseload. Information about the study was distributed to the respective General Managers of the Local Health Offices of the HSE. General Managers distributed the information leaflets to the population of SCWs that had older adults who SN within their caseload. From the responses, the researchers intentionally recruited participants ($n = 7$) who worked at different local health areas for maximum variation of experiences.

## Data collection

Prior to data collection, ethical approval was sought and granted by the local Clinical Research Ethics Committee. Participants were interviewed at their work place in a private room, as this was their choice. Permission to tape record the interviews was granted by all SCWs. Before interviews, participants were reminded of their rights and protections as human subjects and signed a consent form of which they received a copy. Data were collected using in-depth semi-structured interviews, guided by an interview topic guide developed from the literature. The interview guide was piloted prior to use in the study. Interviews were conducted over eight weeks and lasted between forty and 100 minutes. The participants completed a short demographic questionnaire, which is summarised in Table 1. Questions asked included 'How would you define SN and severe SN?' and 'Can you tell me about your views and experiences in working with cases of SN?'. Whilst the interviews were focused, SCWs were encouraged and supported to share their experiences, insights and views on SN.

## Data analysis

The interviews were subsequently transcribed verbatim and data were analysed using content analysis drawing on Burnard's (1991) framework. This type of analysis is appropriate (Polit and Beck, 2004) and particularly useful for qualitative descriptive studies (Sandelowski, 2000). Transcripts were read and re-read while listening to the tapes to become familiar with the

**Table 1** Demographics

| | Male |
|---|---|
| Male | 2 |
| Female | 5 |
| Social work experience 10–15 years | 2 |
| Social work experience 15 years + | 5 |
| Urban and rural | 7 |

data. This was important, as tone of voice and emotions are important to elicit meaning to transcribed words. The transcripts were read to extract significant statements, which were assigned colour codes to aid sorting and organising of data. Codes were examined for connections and were assigned into categories. These categories were placed in separate files and blindly validated by two of the researchers. Patterns of thoughts and beliefs between categories were identified and interpreted and these were developed into themes. Member checking plays an important role in establishing trustworthiness (Polit and Beck, 2004). To that end, two of the participants agreed to critically appraise the researchers' interpretation of the data and the major themes were confirmed.

## Findings

Four central themes emerged relating to self-neglect as an entity, assessment, interventions and ethical issues.

### Self-neglect as an entity

SN as an entity involved distinct but related processes. Self-care can occur along a continuum and a slow deterioration may not be visible. Physical signs were apparent, as described below:

> . . . don't seem to be able to do any day to day activities which include hygiene and self care (SCW 5).
>
> . . . presented with lice all over . . . body not clean (SCW 2).
>
> . . . clothes soiled . . . she was going to the toilet in them . . . was going to the toilet in the bed (SCW 6).
>
> . . . she was sitting in the same black clothes for two years, smell of urine, her nails were long and black, her face was black, the dirt was engrained (SCW 3).

The complexity of cases and underlying morbidities was a concern for a number of the participants, as evidenced in these quotes:

> . . . assessed found not to have a psychiatric illness . . . an addiction problem, very very difficult borderline cognitive impairment but classed as able to make own decisions (SCW 1).
>
> . . . did home visit, brought out a Psycho Geriatrician to assess for capacity psychiatric illness or depression (SCW 4).
>
> . . . seemed to lose touch with the outside world to a degree (SCW 5).
>
> . . . pride as a kind of an issue would not accept any help, actually believed she was still capable of driving her car . . . believing that she was just not

> feeling well this week but was going to be clean next week and this was going on for months (SCW 6).

One participant linked SN with adaptation, as described below:

> . . . what amazed me about her was her resilience . . . she could cope there (living in this seemingly difficult environment) . . . not wanting to be removed . . . because that's not what she wanted, I know that (SCW 7).

Maintaining privacy and clients' reluctance to meet new people was interpreted by one participant as the clients' need to protect the security of their home, as evidenced in this quote:

> . . . very difficult to introduce new people . . . don't like to see their privacy invaded (SCW 5).

Another participant attributed clients' reluctance for social integration as fear of robbery, as stated in this quote:

> . . . she was locking the door at night, bolting herself in because she was afraid of people trying to rob the place (SCW 2).

One participant described social isolation as a factor, as demonstrated in this quote:

> . . . the person had a lot of siblings, all deceased now . . . now lives on her own, doesn't interact as much, quite isolated and kind of withdraws (SCW 1).

Another participant identified that the social network of SN clients attracted people with addiction problems and contributed to the squalor of their environment. Living environment in which clients lived was a factor described by all participants, as evidenced below:

> . . . victims of their lifestyle maybe their parents' lifestyle . . . inherited that lifestyle very old fashioned and unhindered by any modernisation, houses are perishing cold . . . a lifestyle most people in the community would imagine was long gone but its alive and kicking (SCW 1).
>
> . . . how to cook over an open fire, they need electricity, need heating (SCW 3).
>
> . . . don't know how to dispose of rubbish . . . might have the bin outside, but bin is always empty (SWC 5).
>
> . . . the curtains were you know big huge sash windows, the curtains were falling off, they were delicate silk, and they were falling off the walls (SCW 6).
>
> . . . he is living in absolute squalor surrounded by rats, dogs, spiders, that I'd say would be as big, as the dogs, it hasn't been cleaned or changed since about 1940 and he is living like that (SCW 2).
>
> . . . no room to conduct life . . . living in total squalor . . . house absolutely appalling . . . collection of tins, bottles, food, newspapers, empty wrapping

> papers, all over various rooms in the house, . . . animals toileting within the house (SCW 4).

In relation to health, one participant commented:

> Had always been eccentric . . . evidence malnutrition not eating, chronic ill health, refusing to take medication or refusing to see General Practitioner . . . smell decay, appears that she is not coping (SCW 2).

Clients lived in less than safe sanitary conditions and cumulative health behaviours had at times extreme consequences for individuals, their families and sometimes communities, yet clients refused services for various reasons. One of the SCWs provided a vivid description of the consequences of SN:

> Very beautiful woman well kept in earlier years . . . almost 90, refusing all services, . . . not complying with treatment . . . dirt engrained in skin and under nails . . . hair was ragged sat there believing that she was feeling unwell this week going to be clean next week living in a make belief world was it her arthritis got worse maybe pride would not accept help (SCW 6).

The deliberate choices and actions taken by some individuals were seen as 'para-suicide and life threatening', as described below:

> I'm in my 80's . . . lived my life, not depressed, want to pass away, finished with life nobody would be upset, would never commit suicide, suddenly develop anorexia and alcohol issues but don't want interventions (SCW 5).

The reluctance to seek help contributed to SN and ill health but may be a way of life, a choice for them and be at variance with professional views. The consequences of SN were seen by participants to be a major challenge for professionals and services. Early identification of characteristics of self-neglecting behaviours, adaptation and coping could prevent progression to the chronic stage; thus, a comprehensive assessment is of paramount importance.

## Assessment

In the absence of a national definition of SN, the majority of participants indicated inconsistencies in their responses to the suitability of cases to be assessed. For example, these quotes reflect experiences:

> . . . choose whether or not I want to be involved . . . difficult because SN cases are notoriously difficult to manage (SCW 1).

> . . . very careful in screening . . . asking different questions . . . (SCW 6).

> . . . screening to see what's going on there, so many issues and at times it doesn't even come up as self neglect . . . people can cover it up (SCW 4).

Referrals of SN cases can be made to SCWs, EAS from both formal and informal sources. These have been identified as Public Health Nurses (PHNs), nurses in the community, general practitioners (GPs), occupational therapists (OTs), hospital social workers, neighbours, day-care staff, families and police officers, as captured in the following:

> . . . work specifically with family members who contacted me about mother (SCW 6).

> . . . an awful lot (of referrals) come from PHNs, nurses, GPs, OTs, neighbours, other people, day centres, hospital social workers and home helps (SCW 7).

All participants identified that a home visit and establishing a therapeutic relationship in engaging with people who SN were essential. This is clearly articulated in the following statements:

> . . . try to relate to the person, see if they want to make a relationship and not be apprehensive about going in to the house, be respectful, work at the pace of the person (SCW 7).

> . . . build up trust and build up a relationship with the older person (SCW 5).

This may involve lengthy and frequent home visits, which can be challenging, as depicted below:

> . . . we get all these referrals . . . there is SN but to give people a good service . . . I'd rather work with ten people suffering terrible (self-neglect) than give a once in three months visit to 30 people . . . you have to build up that relationship (SCW 6).

> . . . assessment is 'fluid' . . . picking up strands as you go along . . . ongoing (SCW 3).

> . . . people's (previous) experience of SW's and health services . . . so I have to be very open and honest, but yet not say anything that will frighten

**Table 2** Assessment elements

| Personal | Social | Medical | Home environment |
|---|---|---|---|
| Personal appearance (skin, clothing, hair, nails, etc.) | Age<br>History of significant life events | Diabetes, cardiovascular disease, dementia, etc. | Exterior and interior |
| Activities of daily living | Social network | Mental health issues, depression | Neglect |
| Instrumental activities of daily living | Social support | | Squalor |
| Cognitive function | Financial resources | | Hoarding |
| Capacity | Family relationships | | Animals |
| Willingness to take help | | | Health and safety |

> them into shutting the door again . . . I struggle with saying I am a SW because for some people that means you are out (SCW 5).

Assessing whether SN is intentional or non-intentional, using a holistic approach, included a number of elements, as outlined in Table 2. While the detail in Table 2 emerged from the data, there were no specific assessment tools used by participants to guide assessment. Self-report, observational assessment, speaking with SN clients and interviewing health care professionals (PHNs, GPs, nurses), family or people in individuals' social network assisted in identifying needs and risks and supported decision making. Participants identified that careful assessment is needed, as financial exploitation and physical abuse were often hidden behind SN, as illustrated below:

> Presenting problem SN . . . not paying electric bill, no food . . . underlying problem is someone is taking money . . . can't separate SN and abuse (SCW 2).

Individualised assessment and communication across disciplines determined approaches and interventions.

## Interventions

Engaging with clients, building trust over time was critical and all SCWs identified that the intervention approach was very much on an individual basis, as some clients refused services. One participant gave this example:

> Man self-neglecting . . . living alone un-modernised house, 80 yr old sister who is now unwell, getting lift daily (10 miles) to do washing, laundry, meals, cleaning, finances . . . refusing services of home help . . . wants sister to continue caring . . . in hospital should participate in the services to go home . . . difficult man has capacity imagine we will have a battle with his self determination (SCW 1).

One participant described the sensitivity necessary in building a relationship to enable services to be provided:

> . . . it could take three years to get in but we will keep chipping away . . . looking at the life history of the person as to what happened to bring them to this point today and the reason why he/she is frightened of me . . . to decide what intervention is best (SCW 6).

A case conference using a multidisciplinary and multi-agency approach was favoured by the majority, as it assisted in sharing responsibility of an observing role between PHNs, community nurses, GPs and police officers. Even this approach can lead to differences of opinions, as evidenced in this quote:

> . . . you would have very different opinions among the professionals. Some professionals would argue that we just have to interfere where others

> would be very uncomfortable to do anything that would go against the wishes of the older person (SCW 5).

The approach taken at home visits was to introduce themselves as SCWs for older people and no mention was made of the term SN, as SCWs perceive that people would be horrified or threatened by this label. One participant described the importance of the home visit and meeting the person:

> . . . I don't think you can make the decision by just making some initial inquiry or talking to a couple of people, you have to see the environment and you have to meet the person before you can come to any kind of conclusion (SCW 5).

One participant identified using a task-centred approach, or a psychoanalytic approach, asking questions about a range of community-based resources, supports and interventions (benefits, entitlements, meals on wheels, respite, day-care centre) to get a sense of what was acceptable. Being imaginative and using less intrusive services at first were found to be acceptable and one participant identified an intervention used as:

> . . . Leave laundry outside door . . . person picks it up and this tells us person is alive (SCW 1).

The strategies used by participants to keep contact open were many and varied, such as: writing a letter; giving a contact number; sourcing music that the person liked; posting interesting material, so that person will phone when he/she gets it; encouraging reading a chapter in a book on, for example, 'overcoming depression'; or using short-term goal setting, such as getting hair done; going to a dental visit; having toenails done; seeking home improvement grant; hiring a skip to clean up and getting financial advise. The majority of SCWs used the following interventions as stepping stones to supporting people who SN: provision of meals on wheels, home help, respite, day-care centres and counselling services. One participant was conscious of not interfering too quickly, as evidenced in this quote:

> . . . monitoring and getting supports in, keep tipping away, have to be careful . . . if somebody says no to a service when do we leave them, when does it become interfering . . . I'd be conscious of that (SCW 2).

Interventions were individualised to each person. All participants used a wide range of interventions, as detailed above in accessing and supporting cases of SN.

## Ethical issues

A number of challenges were identified by participants and these related to ethical issues, decision-making capacity, resources, caseload management, ongoing support and maintenance, legal issues and education and skills.

The complexity of SN cases presented a number of ethical challenges and determining mental and physical capacity of individuals was critical to the decision-making process. Balancing choice, autonomy and self-determination of older people, respecting actions, behaviours and lifestyle choices in assessing, judging and quantifying risks was complex. Service refusal, no agreed interventions, unacceptability of services to self-neglecting clients and conflicting views between professionals and SN clients in relation to establishing a safe living environment were evident. The following statements capture some of the difficulties faced by participants. When a client stated:

> If you harass me again . . . I will call the police (SCW 2).

> I can't throw aside cases of self neglect . . . try different interventions . . . difficult to close cases . . . time, resources . . . a challenge and dilemma when somebody is living at home in terrible circumstances, services are trying their best to deliver something that is unacceptable to the individual and there is no agreed intervention (SCW 1).

The following statements by two participants capture the dilemmas, worries and powerlessness faced by professionals:

> . . . so if person is found dead under suspicious circumstances or were eaten alive by rats . . . need to be seen to have done everything . . . HSE will inspect files . . .. A challenge accepting that it is their decision their choice, their way of life, no power to make changes . . . walk away now, because not to do so would be disrespectful, unless it effects other people I don't have that right because the greater good has to be my underlying principal (SCW 2).

> . . . some situations . . . person wants to be left alone and live in squalor . . . facing up to the fact that no we can't do anything . . . just having to walk away worried and concerned . . . have to realise and respect that its that persons choice definitely is one of the challenges (SCW 3).

Two participants identified that they were personally challenged but not hampered by a duty to care. They take a more pragmatic view if the person has capacity and feel they must step back and wait for a crisis to occur. PHNs were perceived as being very valued team members in the ongoing management of cases of self-neglect, as their role involves home visiting. This role is illustrated here:

> Do wonders, continue to go in to make sure he/she is okay, when others have given up on the back of their own energy . . . more than any other professional see it maybe as their duty of care (SCW 1).

The absence of a clear framework and legislation on guardianship and capacity creates vulnerabilities for professionals. The 2001 Mental Health Act (Oireachtas Committee) was rarely used. However, Ward of Court is used in certain circumstances, as stated:

> With agreement of psychiatrist, family, a process; done gradually, approach that most people are comfortable with if people can't manage their affairs or

> out of necessity might have assets which need to be accessed . . . a very expensive and slow process (SCW 5).

Sensitivity, respect, non-maleficence to do no harm was a core consideration for all participants. Some participants identified cases in which clients were living in very poor circumstances in severe SN. Some were well-off, had capacity, but refused to spend money and required interventions, as captured in this statement:

> House in mess filth squalor . . . poor self-care . . . no heating no running water . . . electrics are unsafe . . . known to have a good pension (SCW1).

All participants identified that the political and economic climate and budget restraints would create further inequities in accessing a range of community supports and services (medical card, home help, carers' allowance, housing aid for the elderly, sheltered housing), particularly for those who are self-neglecting. The majority of participants identified that they had no specific education on SN to prepare them for the complex challenges faced when working with cases of SN.

## Discussion

This study identified and described the experiences and challenges faced by SCWs, EAS on SN in Ireland. SN is a complex multidimensional problem that is a serious public health issue. There are wide variations in referrals accepted by EAS across the four HSE areas. This research study contributes to the understanding of the practice issues relating to SN nationally and internationally. It brings into focus the complexity of concerns such as assessment, capacity, self-determination, choice, risk, protection and highlights at times the personal challenges and powerlessness faced by SCW, EAS. Previous research has raised dilemmas faced by services and professionals in Australia (McDermott, 2010; McDermott *et al.*, 2009).

One of the themes identified was SN as an entity. SN was seen to present along a continuum of severity ranging from failure to attend to self-care, service refusal, to dilapidated environments, squalor and hoarding of rubbish and animals. These data support previous research that SN does not occur in distinct categories, but along a continuum, ranging from poor personal and environmental care, to severe neglect, where it can be life-threatening (Badr *et al.*, 2005; Reyes-Oritz, 2001). SN cases were described as having underlying morbidities complicated by physical, psychological, social and environmental factors. It was suggested that isolation, poor support networks, service refusal and poor health behaviours had cumulative consequences that were seen by some SCWs to be life-threatening. These findings support previous research linking SN to chronic ill health, dementia, depression, mental and cognitive impairment (Dyer *et al.*, 2005*a*, 2007; Halliday *et al.*, 2000), decreased social

connectivity, alcohol abuse (Burnett *et al.*, 2006; Hurley *et al.*, 2000; Mosqueda *et al.*, 2008; Spensley, 2008), risky behaviour (Badr *et al.*, 2005) and early mortality (Dong *et al.*, 2009).

SN is the largest category of referrals received by EAS in Ireland (O'Dwyer and O'Neill, 2008; HSE, 2009). The concept of SN is complex and referrals received by SCWs EAS are usually extreme cases categorised as 'exceptional circumstances'. As there is no standardised national or international definition of SN (Dyer *et al.*, 2005*a*; HSE, 2009; Payne and Gainey, 2005), there are major differences in opinions and this is reflected in the prevalence of cases identified (HSE, 2009).

The theme of assessment was described by participants as necessitating the establishment of a therapeutic relationship with the client and significant others. The need for a home visit involving the multidisciplinary team was acknowledged as important. Screening and differentiating between intentional and non-intentional SN and obtaining information on personal, psycho-social, medical and home environments were deemed essential. The use of screening instruments by SCWs to support assessment was not evident. Internationally, assessment tools are available and a standardised approach to assessment with clear protocols is favoured for SN (Halliday and Snowdon, 2009; Kelly *et al.*, 2008; Naik *et al.*, 2008; Mosqueda *et al.*, 2008; Pickens *et al.*, 2007; Skelton *et al.*, 2010). It is recommended that a partnership approach between professional and SN clients is central in problem solving, goal planning and intervention planning to seek solutions (Pavlou and Lachs, 2006).

The theme of interventions that emerged described the challenges and multifaceted approaches necessary in meeting the individualised needs of clients. This research study identified that home visiting, case conferences and a multidisciplinary approach were used as intervention strategies. These findings are reflected in previous research by Lauder *et al.* (2005) that supports an interagency approach. Many innovative strategies were used to support SN clients, such as laundry services, reading and writing a letter, and meals and wheels, day-care, respite and counselling were seen as stepping stones to engaging with clients. There are no empirical data on specific interventions with SN clients (Pavlou and Lachs, 2006).

In this study, participants sometimes felt powerless by the complexity of SN cases, balancing autonomy and taking account of capacity, safety and protection issues. Some participants took the approach that, if the person had capacity and was refusing service by choice, they would step back and wait for the crisis to occur. This was achievable when PHNs maintained contact with clients and thus were viewed as being valuable members of the team. This finding is supported by previous research by Hurley *et al.* (2000) that identified the critical role of PHNs in home visiting. In this study, the absence of legislation in guardianship, capacity and a clear policy framework provided further challenges for SCWs. Theses findings support Cooney (2005) and McDermott *et al.*'s (2009) view that the complexity

and diversity of SN cases can present complex ethical and legal challenges for practitioners. McDermott *et al.* (2009) supports a co-ordinated response using a therapeutic approach in decision making, taking account of ethical and legal issues.

In conclusion, SN is a complex multidimensional phenomenon that occurs along a continuum of severity. The lack of a standard definition in addition to the paucity of use of standardised assessment tools contributes to inconsistencies in practice. The intervention most favoured by SCW was a multi-agency and multidisciplinary approach, engaging and building trust with clients to encompass a home visit. Promoting self-determination, balancing risk and protection, taking cognisance of the clients' capacity in the absence of policy frameworks, were some of the challenges experienced by the SCWs.

Recommendations include a clear framework for practice with a definition of SN and clarity on meaning of exceptional circumstances for referral of cases to EAS. Furthermore, best practice was to include the use of valid assessment tools with this client group.

## References


Abrams, R., Lachs, M., McAvay, G., Keohane, D. and Bruce, M. (2002) 'Predictors of self-neglect in community dwelling elderly', *American Journal of Psychiatry*, **159**, p. 1724–30.

Badr, A., Hossain, A. and Iqbal, J. (2005) 'Diogenes syndrome: When self-neglect is nearly life threatening', *Clinics Geriatric*, **13**(8), p. 10–13.

Ballard, J. (2010) 'Legal implications regarding self-neglecting community-dwelling adults: A practical approach for the community nurses in Ireland', *Public Health Nursing*, **27**(2), p. 181–7.

Barocka, A., Seehuber, D. and Schone, D. (2004) 'Messy house syndrome', *MMW Fortschritte der Medizin*, **146**(45), p. 36–9.

Bohl, B. (2010) '*Self-Neglect: Interviews with Adult Protective Service Workers*', Doctor of Philosophy, Ohio State University, Social Work, available online at http://etd.ohiolink.edu/view.cgi?acc_num=osu1281633493.

Bozinovski, S. D. (2000) 'Older self-neglecters: Interpersonal problems and the maintenance of self-continuity', *Journal of Elder Abuse & Self Neglect*, **12**(1), p. 37–56.

Brink, T., Yesavage, J., Lum, O., Heersema, P., Adey, M. and Rose, T. (1982) 'Screening tests for geriatric depression', *Clinical Gerontologist*, **1**, p. 37–43.

Burnard, P. (1991) 'A method of analysing interview transcripts in qualitative research', *Nurse Education Today*, **11**, p. 461–6.

Burnett, J., Regev, T., Pickens, S., Prati, L. L., Aung, K., Moore, J. and Dyer, C. B. (2006) 'Social networks: A profile of the elderly', *Journal of Elder Abuse and Self Neglect*, **18**(4), p. 35–50.

Central Statistics Office (CSO) (2006) *Census 2006 Preliminary Report*, Dublin, Stationery Office.

Clark, A. N. G., Mankikar, G. D. and Gray, I. (1975) 'Diogenes syndrome: A clinical study of gross self-neglect in old age', *The Lancet*, **1**(7903), p. 366–8.

Connolly, M. (2008) 'Elder self-neglect and the justices system: An essay from an interdisciplinary perspective', *Journal of the American Geriatric Society*, **56**, pp. S244–52.

Cooney, C. (2005) 'Diogenes syndrome: A review', *Irish Psychiatrist*, **6**(10), p. 13–16.
Critchley, M. (1953) *The Parietal Lobes*, New York, Hafner.
Day, M. R. (2010) 'Editorial: Self-neglect: A challenge and a dilemma', *Archives of Psychiatric Nursing*, **24**(2), p. 73–5.
Day, M. R., McCarthy, G. and Leahy-Warren, P. (2009) 'Perceptions and views of self neglect: A client-centred perspective', oral presentation at the *National Squalor Conference, 'Pathway through the maze*', Sydney, Australia, 5–6 November.
Day, M. R., McCarthy, G. and Leahy-Warren, P. (2012) 'Perceptions and views of self neglect: A client-centred perspective', *Journal of Elder Abuse and Neglect (accepted for publication)*.
Department of Health (2000) *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*, London, Department of Health.
Dick, C. (2006) 'Self-neglect: Diogenes syndrome and dementia', *The Kansas Nurse*, **81**(9), p. 12–13.
Dong, X. Q., Mendes de Leon, C. F. and Evans, D. A. (2009) 'Is greater self-neglect severity associated with lower levels of physical function?', *Journal of Ageing and Health*, **21**(4), p. 596–610.
Dyer, C. B. and Goins, A. M. (2000) 'The role of the interdisciplinary geriatric assessment in addressing self-neglect in the elderly', *Generations*, **24**, p. 23–7.
Dyer, C. B., Goodwin, J. S., Pickens-Pace, S., Burnett, J. and Kelly, P. A. (2007) 'Self-neglect among the elderly: A model based on more than 500 patients seen by a geriatric team', *American Journal of Public Health*, **97**(9), p. 1671–6.
Dyer, C. B., Heisler, C. J., Hill, C. A. and Kim, L. C. (2005*a*) 'Community approaches to elder abuse', *Clinics in Geriatric Medicine*, **21**(2), p. 429–47.
Dyer, C. B., Toronjo, C., Cunningham, M., Festa, N. A., Pavlik, V. N., Hyman, D. J., Poythress, E. L. and Searle, N. S. (2005*b*) 'The key elements of elder neglect: A survey of adult protective service workers', *Journal of Elder Abuse and Neglect*, **17**(4), p. 1–10.
Esposito, D., Corruble, E. and Hardy, P. (2006) 'Could self-neglect in older adults be a geriatric syndrome?', *Journal of the American Geriatrics Society*, **54**(2), pp. 1946–6(1).
Ewing, J. A. (1984) 'Detecting alcoholism: The CAGE questionnaire', *Journal of the American Medical Association*, **252**, p. 1905–7.
Folstein, M. F., Folstein, S. E. and McHugh, P. R. (1975) '"Mini mental state": A practical method for grading the cognitive state of patients for the clinician', *Journal of Psychiatric Research*, **12**(3), p. 189–98.
Gibbons, S. (2009) 'Theory synthesis for self-neglect: A health and social phenomenon', *Nursing Research*, **58**(3), p. 194–200.
Gibbons, S., Lauder, W. and Ludwick, R. (2006) 'Self-neglect: A proposed new NANDA diagnosis', *International Journal of Nursing Terminologies and Classification*, **17**(1), p. 10–18.
Gill, T. M. (2009) 'Elder abuse: Medical emergency or marker of extreme vulnerability?', *Journal of the American Geriatric Society*, **302**(5), p. 570–1.
Gruenberg, E. M. (1967) 'The social breakdown syndrome: Some origins', *American Journal Psychiatry*, **123**, p. 1481–9.
Gunstone, S. (2003) 'Risk assessment and management of patients whom self-neglect: A "grey area" for metal health workers', *Journal of Psychiatric and Mental Health Nursing*, **10**, p. 287–96.
Halliday, G. and Snowdon, J. (2009) 'The Environmental and Clutter Scale (ECCS)', *International Psychogeriatrics*, **21**(6), p. 1041–51.

Halliday, G., Banerjee, S., Philpot, M. and Macdonald, A. (2000) 'Community study of people who live in squalor', *The Lancet*, **355**, p. 882–6.

Health Service Executive (HSE) (2005) *Policies Procedures and Guidelines for the Care of the Older Adult in the Community*, Health Service Executive, Cork and Kerry Ireland.

Health Service Executive (HSE) (2009) *HSE Elder Abuse Service Developments Open Your Eyes*, Health Service Executive, Ireland.

Hurley, M., Scallan, E., Johnson, H. and De La Harpe, D. (1997) *Survey of Eccentric Vulnerable Adults Living in the Greater Dublin Area*, Dublin, Eastern Regional Health Board.

Hurley, M., Scallan, E., Johnson, H. and De La Harpe, D. (2000) 'Adult service refusers in the greater Dublin area', *Irish Medical Journal*, **93**(7), p. 208–11.

Information and Statistics Division (2009) *Practice Team Information (PTI) Annual Update (2007/08)*, Edinburgh, Information Services, NHS National Services Scotland.

Iris, M., Ridings, J. W. and Conrad, K. J. (2010) 'The development of a conceptual model for understanding elder self-neglect', *The Gerontologist*, **50**(3), pp. 303–15.

Kelly, P., Dyer, C., Pavlik, V., Doody, R. and Jorgerst, G. (2008) 'Exploring self-neglect in older adults: Preliminary findings of the self-neglect severity scale and next steps', *Journal of the American Geriatrics Society*, **56**, pp. S253–60.

Kohlman-Thomson, L. (1992) *Kohlman Evaluation of Living Skills*, 3rd edn, Bethesda, MD, American Occupational Therapy Association.

Kutame, M. M. (2007) 'Understanding self-neglect from the older person's perspective', Ph.D. dissertation, Ohio State University.

Lauder, W. (1999*a*) 'Constructions of self-neglect: A multiple case study design', *Nursing Inquiry*, **6**(1), p. 48–57.

Lauder, W. (1999*b*) 'The medial model and other constructions of self-neglect', *International Journal of Nursing Practice*, **5**, p. 58–63.

Lauder, W., Scott, A. P. and Whyte, A. (2001) 'Nurses' judgements of self-neglect: a factorial survey', *International Journal of Nursing Studies*, **38**(5), p. 601–8.

Lauder, W., Anderson, I. and Barclay, A. (2002) 'Sociological and psychological theories of self-neglect', *Journal of Advanced Nursing*, **40**, p. 331–8.

Lauder, W., Anderson, I. and Barclay, A. (2005) 'Housing and self-neglect: The responses of health, social care and environmental health agencies', *Journal of Interprofessional Care*, **19**(4), p. 317–22.

Lauder, W., Roxburg, M., Harris, J. and Law, J. (2009) 'Developing self-neglect theory: Analysis of related and atypical cases of people identified as self-neglecting', *Journal of Psychiatric and Mental Health Nursing*, **16**, p. 447–54.

Macmillan, H. C. and Shaw, P. (1966) 'Senile breakdown in standards of personal and environmental cleanliness', *British Medical Journal*, **2**(5521), pp. 1032–7.

McDermott, S. (2009) 'The devil is in the details: Self-neglect in Australia', *Journal of Elder Abuse & Self Neglect*, **20**(3), pp. 231–50.

McDermott, S. (2010) 'Professional judgments of risk and capacity in situations of self-neglect among older people', *Aging & Society*, **30**(6), p. 1055–72.

McDermott, S., Linahan, K. and Squires, B. J. (2009) 'Older people living in squalor: Ethical and practical dilemmas', *Australian Social Work*, **62**(2), p. 245–57.

Mosqueda, L., Brandl, B., Otto, J., Stiegel, L., Thomas, R. and Heisler, C. (2008) 'Consortium for research in elder self-neglect of Texas research: Advancing the field for practitioners', *Journal of the American Geriatric Society*, **56**(2), pp. S276–80.

Naik, A. D., Burnett, J., Pickens-Pace, S. and Dyer, C. B. (2008) 'Impairment in instrumental activities of daily living and the geriatric syndrome of self-neglect', *The Gerontologist*, **48**, p. 388–93.

O'Dwyer, C. and O'Neill, D. (2008) 'Developing strategies for the prevention, detection and management of elder abuse: The Irish experience', *Journal of Elder Abuse and Self Neglect*, **20**(2), p. 169–80.

Paveza, G., VandeWeerd, C. and Laumann, E. (2008) 'Elder self-neglect: A discussion of a social typology', *Journal of the American Geriatrics Society*, **56**, pp. S271–5.

Pavlou, M. P. and Lachs, M. S. (2006) 'Could self-neglect in older adults be a geriatric syndrome?', *Journal of the American Geriatric Society*, **54**, p. 831–42.

Payne, B. K. and Gainey, R. R. (2005) 'Differentiating self-neglect as a type of elder mistreatment: How do these cases compare to traditional types of elder mistreatment?', *Journal of Elder Abuse & Neglect*, **17**(1), p. 21–36.

Pickens, S., Naik, A., Burnett, J., Kelly, P., Gleason, M. and Dyer, C. (2007) 'The utility of the Kohlman Evaluation of Living Skills test is associated with substantiated cases of elder self-neglect', *Journal of the American Academy of Nurse Practitioners*, **19**(3), p. 137–42.

Polit, D. F. and Beck, C. T. (2004) *Nursing Research: Principles and Methods*, 7th edn, Philadelphia, Lippincott, Williams & Wilkins.

Reyes-Ortiz, C. A. (2001) 'Diogenes syndrome: The self-neglect elderly', *Comprehensive Therapy*, **27**(2), p. 117–21.

San Filippo, S. M., Reiboldt, W., White, B. and Hails, J. (2007) 'Perceptions of elderly self-neglect: A look at culture and cohort', *Family and Consumer Sciences Research Journal*, **35**, p. 215–32.

Sandelowski, M. (2000) 'Whatever happened to qualitative description?', *Research in Nursing & Health*, **23**, p. 334–40.

Scourfield, P. (2010) 'Reflections on the serious case review of a female adult (JK)', *Journal of Adult Protection*, **12**(4), p. 16–30.

Sherman, B. (2008) 'Geriatric self-neglect: The bill-paying performance test', *Geriatrics*, **63**(2), p. 9–12.

Skelton, F., Kunik, M. E., Regev, T. and Naik, A. D. (2010) 'Determining if an older adult can make and execute decisions to live safely at home: A capacity assessment and intervention model', *Archives of Gerontology and Geriatrics*, **50**, p. 300–5.

Smith, S. (2001) 'Shit is good: Mental health social work with lives of squalor', *Journal of Social Work Practice*, **15**, p. 37–56.

Smith, S. M., Matthews Oliver, S. A., Zwart, S. R., Kala, G., Kelly, A., Goodwin, J. S. and Dyer, C. B. (2006) 'Nutritional status is altered in the self-neglecting elderly', *Journal of Nutrition*, **136**(10), p. 2534–41.

Spensley, C. (2008) 'The role of social isolation of elders in recidivism of self-neglect cases at San Francisco Adult Protective Services', *Journal of Elder Abuse & Self-Neglect*, **20**(1), p. 43–61.

Teaster, P. B., Dugar, T. A., Otto, J. M., Mendiondo, M. S., Abner, E. L. and Cecil, K. A. (2006) 'The 2004 survey of state adult protective services: Abuse of adults 60 years of age and older', Retrieved April 2011 from the National Centre on Elder Abuse available online at: http://www.ncea.aoa.gov/NCEAroot/Main_Site/Library/Statistics_Research/Abuse_Statistics/National_Statistics.aspx.

Thibault, J. M. (2007) 'Analysis and treatment of self-neglectful behaviours in three elderly female patients', *Journal of Elder Abuse & Neglect*, **19**(3/4), p. 151–66.

Working Group on Elder Abuse (2002) *Protecting Our Future*, Dublin, Stationery Office.