CHAPTER 6

Self-Neglect

Ethical Considerations

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ABSTRACT

Self-neglect is a significant international public health issue. Estimates suggest that there may be over one million cases per year in the United States. Aging populations will put more people at risk of self-neglect. This chapter presents background literature, self-neglect definitions and policy context, risk factors, and a brief overview of research on perspectives of self-neglect from both clients and community health and social care professionals. A case study is presented from the perspective of an individual and is used to explore ethical issues therein. A person-centered assessment within a multidisciplinary team approach is required for building a therapeutic relationship with clients. Capacity is a central issue in the management of responses to self-neglect. Ethical considerations of importance for community health and social care professionals include beneficence and nonmaleficence, autonomy and capacity, and respect for people's rights and dignity. A model of ethical justification is presented to explain dilemmas, challenges, and actions. Competence of professionals, multidisciplinary team working, informed consent, privacy, confidentiality, and best interest are also critical considerations. Effective decision making by an interdisciplinary team of professionals needs to be person-centered and give due consideration to the

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best interest of self-neglecting clients. The purpose of this chapter is to provide an in-depth discussion and examination of ethical issues and challenges relating to self-neglecting clients.

BACKGROUND LITERATURE

Self-neglect is a complex multidimensional concept that was first identified in the 1950s. Historically, terminologies used to describe self-neglect have included senile breakdown, (McMillan & Shaw, 1966), senile recluse (Post, 1982), senile squalor syndrome (Clark, Mankikar, & Gray, 1975; Sheikh & Yesavage, 1986), Diogenes syndrome (Reyes-Ortiz, Burnett, Flores, Halphen, & Dyer, 2014), and domestic squalor (Snowdon, Halliday, & Banerjee, 2013). Self-neglect is defined as the behavior of a person that consequently threatens his or her health and safety (Dong et al., 2009). It can vary in presentation and severity but is mainly characterized by profound environmental neglect and cumulative diverse behaviors and deficits that can threaten the person's health, safety, and well-being (Day & McCarthy, 2015; Gibbons, Lauder, & Ludwick, 2006). A case study, illustrating self-neglect sets the context to critically analyze ethical considerations and practice responses to self-neglect.

There are many definitions of self-neglect, but there has been no consensus on a common definition. In addition, there is no one theory that can explain self-neglect. Conceptual models and frameworks have been used to portray self-neglect, for example, medical construct or disease model (Pavlou & Lachs, 2006) and the risk vulnerability model that focus on internal and external vulnerabilities (Paveza, VandeWeerd, & Laumann, 2008). A conceptual model of elder self-neglect captures the physical/psychosocial and environmental influences and embraces a wide array of individual and population-level determinants of health (Iris, Ridings, & Conrad, 2010). Gibbons (2009) theorized self-neglect from a behavioral perspective and differentiated between "intentional" and "nonintentional" self-neglect and key factors related to insight, readiness, coping, and ability of the person to meet complex health and social care factors.

Self-neglect is associated with depression, dementia, executive dysfunction, reduced physical function, old age, living alone, poor social networks, alcohol and substance abuse, economic decline, and poor coping (Gibbons, 2009; Pickens et al., 2013). Self-neglect can occur in younger and older people, but research has mainly focused on older people (Lauder, Roxburgh, Harris, & Law, 2009). Age-associated morbidities are largely absent in younger people, suggesting that it may be somewhat different in this age group (Iris et al., 2010). Younger people who displayed features of self-neglect portrayed

fractured chaotic life histories, that is, alcohol/drug addictions, poor physical function, and health issues (Lauder et al., 2009). Traumatic life circumstances influenced the way younger and older people coped over time (Band-Winterstein, Doron, & Naim, 2012; Day, Leahy-Warren, & McCarthy, 2013). There is a connection between self-neglect, animal hoarding, animal cruelty, and social isolation (Devitt, Kelly, Blake, Hanlon, & More, 2014). Animal hoarding may be a symptom of a physical or psychological disorder (Patronek & Nathanson, 2009).

Self-neglect accounts for the highest number of referrals, approximately 1.2 million cases, to Adult Protective Services (APS) in the United States annually (O'Brien, 2011). Prevalence of self-neglect is expected to escalate as populations age. The prevalence of risk is reported to be higher in older black people (85+ years; 10.1%; Dong, Simon, & Evans, 2012a). Low income (≤USD 15,000) is associated with increased prevalence of risk in men (21.7%) and women (15.3%; Dong, Simon, & Evans, 2010a). Data from general practitioner caseloads in Scotland reported that prevalence rates varied from 166 to 211 per 100,000 populations (Lauder & Roxburgh, 2012), and to date, there is no available data in England. In Ireland, elder self-neglect cases account for 18%–20% of the referrals received by Senior Case Workers (SCWs). The criteria for referral to SCWs is people aged 65 years and above who are living in conditions of extreme self-neglect, which is not well defined (Health Service Executive, 2012). Approximately 59% of the referrals come from Public Health Nurses (Health Service Executive, 2013). These estimates do not reflect a true picture of the continuum of self-neglect across populations, and, furthermore, underreporting and nonengagement are issues in this population group. Self-neglect is a serious and understudied public health issue internationally. Vulnerabilities for self-neglect will increase as populations age and this will present unique complex challenges for both health-care and other professionals and society in general.

Self-neglect clients have significantly higher health-care costs compared with other similar client groups (Franzini & Dyer, 2008). The potentially serious adverse implications associated with self-neglect include significantly increased mortality (Reyes-Ortiz et al., 2014); hospice admission (Dong & Simon, 2013); nursing home placement (Lachs, Williams, O'Brien, & Pillemer, 2002); hospitalization (Dong, Simon, & Evans, 2012b); increased emergency department (ED) visits (Dong, Simon, & Evans, 2012c); caregiver neglect (Dong, Simon, & Evans, 2013); and emotional and financial abuse (Mardan, Jaehnichen, & Hamid, 2014). The question often asked is, does self-neglect arise as a consequence of elder abuse or does elder abuse lead to self-neglect? The cause and effect relationship between self-neglect and elder abuse is unclear and Professor

Desmond O'Neill (personal communication, January 31, 2014) contends that self-neglect is "occult elder abuse."

Self-neglect is an emerging, pervasive, complex, and challenging problem, and it is critical that decisions made by health and social care professionals are evidence and skills based and give due consideration to ethical, legal, and policy contexts (Day & McCarthy, 2015). This chapter provides an overview of self-neglect definitions and policy context of self-neglect, executive functioning (EF) and self-neglect, and explores perspectives and understanding of self-neglect from clients and health and social care professionals.

SELF-NEGLECT: DEFINITIONS AND POLICY CONTEXTS

Different definitions and policy contexts and different service approaches are used internationally in the safeguarding and protection of people who self-neglect (Department of Health, 2000, 2014; McDermott, 2010; Working Group on Elder Abuse, 2002). Self-neglect is included in the lexicon of elder abuse definitions in many states in the United States (Teaster, Dugar, Mendiondo, Abner, Cecil, & Otto, 2006) and some APS laws in, for example, Texas do not require distinction between self-neglect and neglect by others (Choi, Kim, & Asseff, 2009). In addition, the term *vulnerable adult* is often used in the context of self-neglect (Ohio Department of Job and Family Services, 2013). The Elder Justice Act (2010) statutorily defined self-neglect as "an adult's inability due to physical or mental impairment, or diminished capacity, to perform essential self-care tasks" (p. 4).

Central to this definition is inability due to cognitive or functional impairment to meet basic health and safety needs and finances. This definition excludes a mentally competent older person who understands the consequences of decisions. Poythress, Burnett, Naik, Pickens, and Dyer (2006) differentiate types of self-neglect by including "inability or unwillingness" in the definition of self-neglect (p. 7). Nurse researchers developed a nursing diagnosis and definition of self-neglect that differentiated intentional and unintentional self-neglect. This captures the choice factors as well as sociocultural influence of the behavior and potential of the negative impact for the individual, the family, and community (Gibbons et al., 2006). In the United States, legislation requires mandatory reporting of self-neglect to APS.

In contrast, Ireland, Scotland, United Kingdom, and Australia do not categorize self-neglect as a form of elder abuse and neglect, as it does not happen within a relationship (Health Service Executive, 2014a; Lauder, 1999; McDermott, 2010). In Ireland, *Protecting Our Future* policy document (Working Group on Elder Abuse, 2002) provided the framework and context for the

establishment of elder abuse services and 32 specialist SCWs who are social workers were appointed in 2007. The complexity and uniqueness of the challenges of self-neglect cases present led to a national procedural policy for responding to "extreme self-neglect" cases in 2009 (Health Service Executive, 2012). The policy document *Safeguarding Vulnerable Persons at Risk of Abuse* has included "extreme self-neglect" as a dimension of self-neglect (Health Service Executive, 2014b). There is no mandatory reporting of elder abuse or self-neglect in Ireland, and self-neglect is not included in the definition of elder abuse.

There are divergent views as to whether self-neglect should be included in the definition of elder abuse (Lauder, Anderson, & Barclay, 2005). Some argue that inclusion in elder abuse is appropriate (O'Brien, 2011), while other researchers argue that it creates confusion and ambiguity (Doron, Band-Winterstein, & Naim, 2013). Nevertheless, self-neglect can present simultaneously with elder abuse (Health Service Executive, 2014a). The etiology of self-neglect is multifactorial, and determination of behavior is poorly defined in relation to underlying causes and effects (Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly, 2007; Pickens, 2012). Many risk factors associated with self-neglect have the potential to adversely impact the capacity of individuals to live independently and remain connected with their community as they age. Details are presented in Table 6.1.

Executive Function and Self-Neglect

Self-neglect is associated with multiple comorbidities and many of these can lead to mental health issues, for example, depression and cognitive dysfunction

TABLE 6.1
Risk Factors

- Cognitive impairment (e.g., depression, dementia, executive dysfunction)
- Multiple morbidities (cardiovascular disease, hypertension, diabetes, malnutrition, etc.)
- Poor/reduced social networks, living alone
- Poverty, poor economic circumstances, deprivation
- Traumatic life history (e.g., abuse in early years, bereavement, divorce, chaotic lifestyles due to mental health issues, and drug or alcohol abuse)
- Poor coping
- Older age and mental status problems strongly associated with global neglect behaviors

Source: Bozinovski (2000); Burnett et al. (2014); Burnett et al. (2006); Choi et al. (2009); Gibbons (2009); Lauder et al. (2009).

(Abrams, Lachs, McAvay, Keohane, & Bruce, 2002; Dong, Simon, et al., 2010b; Dong, Wilson, Mendes de Leon, & Evans, 2010c). Greater self-neglect has been associated with poor performance in episodic memory, perceptual speed, and executive tasks (Dong, Simon, et al., 2010b). A decline in episodic memory and EF can be an indicator of early Alzheimer's disease. EF (frontal lobe function) is necessary for planning, initiation, organization, self-awareness, and execution of tasks and is critically important for protection and safety and independent living. Executive dysfunction inhibits appropriate decision making and problem solving (Hildebrand, Taylor, & Bradway, 2013). The perceptions of six clients living in squalor who had deficits in EF and impaired memory were examined by Gregory, Halliday, Hodges, and Snowdon (2011). Five individuals aptly comprehended and assessed photographs of squalor situations; four displayed concern for persons living in such circumstances but did not transfer concerns to their own physical and personal living situation. A decline in EF was associated with severity of self-neglect (Dong, Simon, et al., 2010b) and EF may be an important factor in older adults who self-neglect (Pickens et al., 2013). To identify EF in individuals with self-neglect, a battery of EF tests need to be administered and completed (Pickens et al., 2013). The Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975) is the most widely used tool for assessment of cognition by community nurses but does not measure EF. Judgement and determination of capacity and understanding self-neglecting clients' views of their situation is critical.

Clients' Perspectives and Understanding of Self-Neglect

A dearth of research has captured the meaning and experiences of individuals who self-neglect, and their perspectives are particularly important for understanding self-neglect phenomena. Bozinovski (2000) used a constructivist grounded theory approach (Charmaz, 1991) to gain insight into perceptions, understanding, and feelings of older self-neglecting adults. The findings identified that self-neglecting participants continuously strove to maintain customary control within their everyday lives as they dealt with a range of threats and challenges. Participants did not see their behaviors as self-neglecting as they strove to maintain independence. However, behaviors were often dysfunctional as capacity started to fail. Individuals felt threatened and distrustful when people interfered. Bozinovski (2000) identified two social psychological processes, "preserving and protecting identity" and "maintaining customary control" as an explanation for much of the self-neglect behavior. The researcher maintained that the term "self-neglect" as currently applied is a misnomer (p. 54).

Kutame (2008) used a multiple case study design involving 12 individuals and noted that participants did not interpret their behavior as one of self-neglect

and saw the problems as outside of their own control. They recounted that they strove to do their best to look after themselves and "make ends meet" but at times they had to "let other things go" (Kutame, 2008, p. 171). Band-Winterstein et al. (2012) described experiences and meaning of 16 self-neglecting individuals. Four key themes emerged: "I was unlucky"; "That is the way it is"; "They tell me that I am disabled"; and "My empire." Participants wished that people would recognize their attributes and look beyond the presenting external image. Self-neglect was not related solely to old age. Life history and narratives recounted traumatic sufferings (loss of family members, divorce, migration, violence, and traumatic life events), and this changed the way older people coped with life. Participants described their lives as normal, while professionals viewed their behaviors as "personal and medical neglect" (p. 6). Day et al. (2013) described a combination of comorbidities and social issues including alcohol abuse, grief, fear, helplessness, isolation, institutionalization, and childhood abuse among people who self-neglect. Participants' living and personal circumstances were diverse. These ranged from having no home, water, sanitation, or electricity to living in severe squalor, with varying degrees of hoarding, frugality, odors, unkempt appearance, and poor self-care. The majority of participants did not feel vulnerable or see any immediate problems similar to previous research (Band-Winterstein et al., 2012; Bozinovski, 2000; Kutame, 2008). The meaning and descriptions suggest that the alternative behaviors and choices adopted by participants named as "self-neglect" may be their way of trying to cope and survive. Similarly, Gibbons (2009) concluded that coping abilities and personal beliefs were factors in intentional self-neglect situations. The choices of people who self-neglect over a long period need to be viewed in the context of their lives and stories. The term *self-neglect* suggests the problem is with the individual and does not acknowledge the contextual issues, which can be problematic. Home care nurses in the United States believe that people who self-neglect see their situation as "normal" (O'Connell, 2015).

Health and Social Care Professionals' Perspectives of Self-Neglect

Community health and social care professionals, especially community nurses and social workers, have always played a key role in supporting vulnerable population groups. These include clients with multiple comorbidities, individuals living in poor neighborhoods, and those who are socially isolated, frail, and at risk for elder abuse and self-neglect. The concept of self-neglect is socially constructed and judgement of risk is socially and culturally defined (Bohl, 2010; Eisikovits, Koren, & Band-Winterstein, 2013; McDermott, 2010). The perspectives of professionals and their clients can differ significantly. Severe self-neglect cases are more often referred to specialist services, and responses are at the

discretion of the formal system. Self-neglect cases pose particular challenges and if they are not categorized as extreme self-neglect, they are not prioritized by professionals due to demanding caseloads (O'Donnell et al., 2012).

Gunstone (2003) found some agreement among community mental health workers in relation to the classification of self-neglect but no agreement on the definition of severe self-neglect. Exploitation by others and financial and sexual abuse were elements of self-neglect identified. A critical component of risk assessment was building a therapeutic relationship, establishing if self-neglect was active or passive (competence), and ascertaining information on recent and past life story. Decision making was supported by team process, ongoing assessment, interagency policy and procedures, and individual supervision.

Dyer et al. (2006) examined perspectives of APS specialists (n = 24) of the indicators for validation of self-neglect. The participants identified 125 indicators of self-neglect and described them in terms of deficiencies in environment, personal hygiene, and cognition. Assessment of client's decision-making capacity was a concern, and training, experiences, and "gut feelings" supported validation of self-neglect. The term self-neglect was used infrequently by community organization professionals in Australia and was associated more with acute risks (noncompliance with medical treatment, falls, visible pressure sores, self-harm, and psychosis) that warranted intervention (McDermott, 2008). Squalor was used frequently to describe situations that involved extreme environmental uncleanliness that included "presence of vermin and animals, garbage and waste and resultant odours" (p. 239). Health-care providers readily declined involvement with environmental neglect situations, and this created tension and frustration among professionals in other organizations. Professional judgements on causes of self-neglect were based on formal health assessments and decisions were influenced by organizational background (McDermott, 2010). Poor nutrition, falls, visible sores, self-harm and psychosis were acute risks for self-neglect. Squalor was perceived to be more dangerous and mortality risk was higher and required an immediate response. Participants agreed that medical assessments were necessary to assess if people were legally capable of making decisions.

Bohl (2010) described how APS workers assess and treat elder self-neglect. Self-neglect was constructed and operationalized by ethical and legal considerations, largely due to their role. They articulated that assessment of decision-making was central and questions needed to relate to capacity; personal health and hygiene; housing; relationships; and finances (p. 131). Participants highlighted the importance of honoring people's self-determination and right to refuse services when they were assessed as competent. In many of the studies outlined in the preceding text, the assessment methods used were not articulated in publications, leading to a conclusion that a valid and reliable method

of assessment of self-neglect is not available. The majority of SCWs in Ireland indicated that there was no self-neglect assessment tool in use and classification of "extreme self-neglect" was open to interpretation (Day, McCarthy, & Leahy-Warren, 2012). The complexity of cases presented many challenges, and lack of legislation in guardianship and capacity contributed to feelings of powerlessness among community health and social care professionals.

Doron et al. (2013) utilized a phenomenological approach to understand aspects of self-neglect from 14 SCWs in Israel. Participants had difficulty in conceptualizing and defining characteristics of self-neglect and linked it with abuse and neglect. Managing self-neglect cases raised contradictory feelings, that is, disgust and rejection, empathy, and burnout. Community responses that disregard clients' rights and choices including refusal to engage with services can create conflict. Encounters with self-neglecting clients present ethical, personal, and professional challenges with regard to duty to care, respecting clients' autonomy, and refusal of intervention. The complexities of self-neglect cases coupled with conflicting values, beliefs, and principles of clients, professionals, and communities on balancing risk and safety issues can create ethical dilemmas and influence response and interventions. A case study of self-neglect is presented that illuminates the complexity of ethical dilemmas and assessment and management challenges therein. The difficulties in responses for health and social care professionals are outlined.

THE CASE BASED ON A HOME VISIT (DAY ET AL., 2013)

Arthur (name and details changed) was a 71-year-old single man, housebound, who lived alone. Arthur's home was a single-story terraced house in a small rural town. The building was a solid structure but looked dilapidated, the windows were black with dirt, and there were no locks on inner doors that were held back with empty barrels. Arthur's living room and kitchen were very neglected and in need of considerable home maintenance, and there were no cooking facilities. The living room was cold with no home comforts, the open fire was full of rubbish, and the floor was barely visible underneath heaps of rubbish, empty bottles of alcohol, and empty fast-food containers. In the living room, Arthur had a bed with no bedding clothes and the mattress was bare, dirty, and discolored; this was where he spent his days and nights. His general appearance was slim and hardy with evidence of filthy personal appearance (lack of hygiene, ingrained dirt on skin, shoddy dirty clothing, bad odor, disheveled appearance, etc.). Arthur had four cats that were positioned among the mounds of rubbish in the living room, a young puppy was running around freely, and there was a nasty odor of animal excrement.

Arthur's Script

My name is Arthur and I am one of three sons born to an Irish mother and I never knew my father. I had no relationship with my mother and my memory of her is poor. I have very poor memories of my mother, I do not wish to talk about her, and I would describe her as a "loose woman," a "prostitute." It is enough to say that my very early memories were: I was often alone and hungry for long periods and my single mother was unable to care for me and my brothers. My two older brothers and I were taken from my mother and moved into institutional state care when I was four years old.

Growing up in the institution was very difficult and many things happened there that I do not want to talk about and did not talk about for many years. I lived for 14 years in an Industrial school and left there when I was 18 years old. I immigrated to another country but life skills did not prepare me for this new and strange world outside of an institution.

Unskilled, I worked wherever I could, labouring on farms and building sites. I had what could be described as a nomadic lifestyle. I had no fixed abode and lived in different places over the years. These included a tent, a ditch on the side of the road, farmers sheds, and sometimes I resided in lodgings or took a room at an inn. I had no friends and was disconnected from family, and I sought refuge in the evenings in the local inn or ale house. I became very fond of the drink and frequently got into arguments and fights due to my severe drinking. I was unable to relate to women or people and was unable to form any lasting friendships and felt inferior and was isolated. I never returned to Ireland during these chaotic years and I avoided seeking out information on my brothers and never made contact with my extended family.

In 2009, I returned to Ireland and I was aged 65 years. I did odd farm labouring jobs to survive, my transport was a push bike and I lived in a caravan that leaked water. I met up with my brothers and discovered that my two brothers and I were among the many children that had been victims of child sexual abuse while under the protection of the State in Ireland. I applied and received a settlement like many other survivors of abuse under the Redress Board or Court awards. This changed my financial circumstances and the court provided money for the purchase of my first home. I have no relationship with my brothers and my extended family and I have no need for one. My family are my surrogate pup and my four cats who I love dearly. My home is a palace.

Ethical Considerations

Many ethical conflicts arise in health and social care delivery systems, and safeguarding and protecting older people who self-neglect can present ethical dilemmas such as those profiled in the preceding subsection. A central

principle in nursing ethics and core values central to the code of ethics of nurses and midwife professionals is respecting the uniqueness of each person and his or her choice, autonomy, and self-determination as a basic human right (American Nurses Assocciation, 2015; Nursing and Midwifery Board of Ireland, 2014).

Asking "How should I act?" in this case leads to finding an answer within the relationship. Realizing and respecting that it is Arthur's choice is one of the challenges. Mary, a neighbor, made telephone contact with the community nurses, as she was worried about Arthur's living circumstances. The community nurse did a home visit. The observed and assessed vulnerabilities based on a comprehensive holistic assessment included extreme environmental neglect, poor hygiene, reduced physical function, low physical activity, underweight, and bullying from teenage children. Arthur was dependent on two neighbors for all his shopping needs, and they had also informally taken responsibility for obtaining money from Arthur's bank account. While it was laudable of the neighbors to be helpful and concerned, Arthur was vulnerable. Assessment of self-neglect was subjective. Some authors support the use of standardized self-neglect assessment tools (Day, 2015; Day et al., 2013; McDermott, 2010; Naik, Teal, Pavlik, Dyer, & McCullough, 2008).

The community nurse asked Arthur to use his money to employ a cleaning service and a painter. Home help services were offered to Arthur, but he was very clear that he did not want people coming into his home and making any changes. The community nurse referred the case to the SCW, protection of older people services and also made contact with the general practitioner. After several home visits and a multidisciplinary team meeting, there were different views expressed on what decisions and responses were required. Two of the most significant deliberations in cases of self-neglect are determining (a) if the person is competent and (b) if the person is safe to live in these circumstances.

The model of ethical justification in a case of elder abuse (Linzer, 2004) was revised, and a new adapted version for the context of self-neglect is presented in Table 6.2. This seeks to understand values, rules, principles, actions, and ethical challenges of clients and community professionals. It is understood from the case presentation that independence and autonomy are values and principles acknowledged by Arthur. He values living independently in his own home where he feels safe. The question is whether he has the mental capacity to make an informed choice about his behavior and way of living. Does Arthur comprehend and understand the degree of risk and dangers involved in his current living situation? Many older people have diminished cognition and physical impairment, and elements that need to be evaluated are vulnerability, safety, and capacity for self-determination (Harnett & Greaney, 2008;

TABLE 6.2
Model of Ethical Justification in a Case of Self-Neglect

	Values	Rules	Principles	Actions
Client (self-neglect)	Being independent and living in his own home; Arthur's choice is to remain in current situation	Informed consent must be obtained for a home visit and before executing services	Respect for autonomy and self-determination	Seeks help for shopping and accessing money, accepts home visits, refuses any interventions or cleaning services
Community health and social care professionals	Therapeutic relationship between community health and social care professional and the client that is based on trust, understanding, compassion, and support serves to empower the client to make life choices Ensuring ethical practice of community nursing and social work is embedded in national and international codes of ethics Maintaining the highest standards of quality is foremost	Informed consent is necessary prior to intervention	Respect choice, autonomy, and self-determination. Resolve ambiguity in duty of care/best interest Social justice (challenging discrimination, recognizing diversity, working in solidarity with team members, and challenging unjust policies and practice)	Multidisciplinary team approach in management of risk: intervene/duty of care vs. do not intervene Whose best interest? What are the risks if we intervene? Wait for change in situation

Lee & Kropf, 2013). Self-neglect due to impaired cognition and executive dysfunction is common, but cognitive dysfunction is not an essential antecedent to self-neglect.

Assessment of Arthur's capacity is critical. Capacity is a complex attribute that is specific to decision making. It requires the ability to understand the consequences of a decision but also the ability to execute decisions and to adapt plans (Dyer et al., 2007). To be considered informed, Arthur has to demonstrate awareness of the possible risks, benefits, and consequence of his behaviors and his actions. Assessment and evaluation of decision-making capacity requires the person to articulate and demonstrate the ability to execute decisions. Observations and questions will support the evaluation of Arthur's everyday functioning, problem-solving skills, judgments, decisions, and understanding relative to managing his finances, nutrition, medical care, and living circumstances (Naik et al., 2008). Arthur demonstrated capacity here and now. In the evaluation and assessment of risk, MacLeod and Stadnyk (2015) identified seven key factors: the client's capacity and his or her support, the occurrence, imminency and frequency of the event, the severity of the consequences, and the number of other events co-occurring (p. 46). Self-neglect is a complex multidimensional problem. Records need to give careful consideration to each of the above factors, clearly document the chronology of service/agency involvement, identify manager to take lead responsibility in management of risk and each identified need requires documentation on responses, interventions and outcomes.

Divergence of opinions can emerge in respect of actions to be taken. Ethical concerns can create tension and reduce opportunities for negotiation and reciprocity for effective multidisciplinary team working and compromise relationships with Arthur. Surveillance and case management of self-neglect cases can be challenging in the current economic climate and reduce opportunities for relationship building.

One community nurse's view was that "duty of care" necessitated a service response but justifying this action would not respect Arthur's capacity, choice, or autonomy. According to SCWs, community nurses are key professionals in the management and identification of self-neglect and their need to do something may relate to their duty of care and caring role (Day et al., 2012). They continue to negotiate with clients while others walk away. Mary, the neighbor, stated that Arthur should not be left to live like this and firmly expressed that it was the responsibility and duty of the community health and social services to do something about the situation. The SCW advocated that as Arthur has capacity and the degree of risk and endangerment was negligible, he had a right to his self-determination and autonomy. SCWs take a more pragmatic approach, stepping back when a person has capacity (Day et al., 2012). Arthur views his home as a palace

and his dogs and cats as his family. Arthur may view intervening as authoritative. His determination and autonomy may feel threatened and distrustful and is more likely to refuse future access to his home and reject future interventions.

Engagement, responsibility, and sensitivity to cultural differences are key components of ethical professional practice. A relational response to vulnerable adults at risk of self-neglect recognizes that people's experiences are shaped by complex interplay and social determinants of health (Doane & Varcoe, 2008). The moral foundation of community nursing practice is nurse–client relationships. Building a therapeutic relationship with clients is a key factor (Gunstone, 2003). In recognition of Arthur's vulnerability, continuing efforts by a community nurse to engage with Arthur will potentially lead to long- or short-term solutions based on Arthur's preferences. Self-neglect situations can evolve over many years and are high risk for change over time (Day, Mulcahy, Leahy-Warren, & Downey, 2015). Ongoing assessment of capacity and evaluation of risk will need to take place. Part of the challenge is knowing what to do and understanding whose best interest is being met.

Paternalism, as defined by Beauchamp and Childress (2001), needs careful consideration in Arthur's case: "The intentional overriding of one's person known preference or actions by another person, where the person who overrides justifies the action by the goal of benefitting or avoiding harm" (p. 274).

This approach is not person-centered and does not respect Arthur's rights, choice, freedom, autonomy, and self-determination. The rules of informed consent would be dismissed in consideration of his "best interest." Prevention in safeguarding is about empowering Arthur to make small changes and it is not about being overprotective. State policy and laws on self-neglect are extremely diverse regarding, for example, categories of abuse, definitions, eligibility, mandatory reporting, scope of services, penalties, and guardianship. Community health and social care professionals need to be guided by the philosophies, safeguarding policies, protocols, and clinical guidelines of their member states and countries (Health Service Executive, 2014b; White, 2014). Effective best practice requires good governance structures, comprehensive procedural guidelines, collaboration and sharing of information, supportive supervision, and a person-centered approach (Braye, Orr, Preston-Shoot, & Penhale, 2015). Paternalistic approaches can emerge in the handling of self-neglect cases.

In conclusion, community health and social care professionals have a collective response as part of the multidisciplinary team in enabling and supporting vulnerable older people like Arthur to live in dignity and safety in their own home for as long as possible. Effective decision making needs to balance choice, control, self-determination, independence, and well-being and requires sensitivity, reflection, and careful evaluation of all options. Ethical dilemmas arise when

perspectives differ. Arthur's case study portrays and describes how past and present social conditions were shaped biologically, psychologically, interpersonally, and culturally. Contextualizing risk and relationally entering into Arthur's situation and undertaking a comprehensive holistic assessment is a necessity. Multidisciplinary working is key, as is ongoing review and assessment of capacity and risk. Self-neglect can present significant demands and ethical challenges for health-care providers and professionals. Community health and social care professionals need training in self-neglect and risk assessment of clients. This is to ensure that they are reflective, knowledgeable, and skilled in safeguarding older people vulnerable for self-neglect. Empirical research into ethical issues including how community nursing and social workers conceptualize and handle ethical difficulties and self-neglect is required.

REFERENCES

Abrams, R. C., Lachs, M., McAvay, G., Keohane, D. J., & Bruce, M. L. (2002). Predictors of self-neglect in community-dwelling elders. *American Journal of Psychiatry, 159*(10), 1724–1730.

American Nurses Assocciation. (2015). *Code of ethics for nurses with interpretive statements*. Retrieved from http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/Code-of-Ethics-For-Nurses.html

Band-Winterstein, T., Doron, I., & Naim, S. (2012). Elder self neglect: A geriatric syndrome or a life course story? *Journal of Aging Studies, 26*(2), 109–118.

Beauchamp, T., & Childress, J. (2001). *Principles of biomedical ethics*. Oxford: Oxford University Press.

Bohl, W. (2010). *Investigating elder self-neglect: Interviews with adult protective service workers* (Electronic Thesis or Dissertation). Retrieved from https://etd.ohiolink.edu/

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

Braye, S., Orr, D., Preston-Shoot, M., & Penhale, B. (2015). Learning lessons about self-neglect? An Analysis of serious case reviews. *The Journal of Adult Protection, 17*(1), 3–18.

Burnett, J., Dyer, C. B., Halphen, J. M., Achenbaum, W. A., Green, C. E., Booker, J. G., et al. (2014). Four subtypes of self-neglect in older adults: Results of a latent class analysis. *Journal of the American Geriatrics Society, 62*(6), 1127–1132.

Burnett, J., Regev, T., Pickens, S., Prati, L. L., Aung, K., Moore, J., et al. (2006). Social networks: A profile of the elderly who self-neglect. *Journal of Elder Abuse & Neglect, 18*(4), 35–49.

Charmaz, K. (Eds.). (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Choi, N. G., Kim, J., & Asseff, J. (2009). Self-neglect and neglect of vulnerable older adults: Reexamination of etiology. *Journal of Gerontological Social Work, 52*(2), 171–187.

Clark, A. N. G., Mankikar, G. D., & Gray, I. (1975). Diogenes syndrome clinical study of gross self-neglect in old age. *The Lancet, 1*(7903), 366–368.

Day, M. R. (2015). *Self-neglect: Development and evaluation of a self-neglect (SN-37) Measurment instrument*. Unpublished doctoral dissertation. University College Cork, Ireland.

Day, M. R., Leahy-Warren, P., & McCarthy, G. (2013). Perceptions and views of self-neglect: A client-centered perspective. *Journal of Elder Abuse & Neglect, 25*(1), 76–94.

Day, M. R., & McCarthy, G. (2015). A national cross sectional study of community nurses and social workers knowledge of self-neglect. *Age and Ageing, 44,* 717–720. Retrieved from http://ageing.oxfordjournals.org/content/early/2015/03/06/ageing.afv025.abstract

Day, M. R., McCarthy, G., & Leahy-Warren, P. (2012). Professional social workers' views on self-neglect: An exploratory study. *British Journal of Social Work, 42*(4), 725–743.

Day, M. R., Mulcahy, H., Leahy-Warren, P., & Downey, J. (2015). Self-neglect: A case study and implications for clinical practice. *British Journal of Community Nursing, 20*(3), 110, 112–115.

Department of Health. (2000). *No secrets*. London: Department of Health.

Department of Health. (2014). *Care act 2014.* Retrieved from http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Devitt, C., Kelly, P., Blake, M., Hanlon, A., & More, S. J. (2014). Dilemmas experienced by government veterinarians when responding professionally to farm animal welfare incidents in Ireland. *Veterinary Record Open, 1*(1). Retrived from http://vetrecordopen.bmj.com/content/1/1/e000003.full

Doane, G. H., & Varcoe, C. (2008). Knowledge translation in everyday nursing: From evidence-based to inquiry-based practice. *Advances in Nursing Science, 31*(4), 283–295.

Dong, X., Fulmer, T., Simon, M., Mendes de Leon, C., Fulmer, T., Beck, T., et al. (2009). Elder selfneglect and abuse and mortality risk in a community-dwelling population. *Journal of the American Medical Association*, *302*(5), 517–526.

Dong, X., & Simon, M. A. (2013). Association between elder self-neglect and hospice utilization in a community population. *Archives of Gerontology and Geriatrics, 56*(1), 192–198.

Dong, X., Simon, M. A., & Evans, D. A. (2012a). Prevalence of self-neglect across gender, race, and socioeconomic status: Findings from the Chicago Health and Aging Project. *Gerontology, 58*, 258–268.

Dong, X., Simon, M. A., & Evans, D. A. (2012b). Elder self-neglect and hospitalization: Findings from the Chicago Health and Aging Project. *Journal of the American Geriatrics Society, 60*(2), 202–209.

Dong, X., Simon, M. A., & Evans, D. A. (2012c). Prospective study of the elder self-neglect and ED use in a community population. *The American Journal of Emergency Medicine, 30*(4), 553–561.

Dong, X., Simon, M., A., & Evans, D. A. (2013). Elder self-neglect is associated with increased risk for elder abuse in a community-dwelling population: Findings from the Chicago Health and Aging Project. *Journal of Aging and Health, 25*(1), 80–96.

Dong, X., Simon, M. A., & Evans, D. A. (2010a). Cross-sectional study of the characteristics of reported elder self-neglect in a community-dwelling population: Findings from a population-based cohort. *Gerontology*, *56*(3), 325–334.

Dong, X., Simon, M. A., Wilson, R. S., Mendes de Leon, C. F., Rajan, K. B., & Evans, D. A. (2010b). Decline in cognitive function and risk of elder self-neglect: Finding from the Chicago Health Aging Project. *Journal of the American Geriatrics Society, 58*(12), 2292–2299.

Dong, X., Wilson, R. S., Mendes de Leon, C. F., & Evans, D. A. (2010c). Self-neglect and cognitive function among community-dwelling older persons. *International Journal of Geriatric Psychiatry, 25*(8), 798–806.

Doron, I., Band-Winterstein, T., & Naim, S., (2013). The meaning of elder self-neglect: Social workers' perspective. *The International Journal of Aging and Human Development, 77*(1), 17–36.

Dyer, C. B., Goodwin, J. S., Pickens-Pace, S., Burnett, J., & Kelly, P. A. (2007). Self-neglect among the elderly: A model based on more than 500 patients seen by a geriatric medicine team. *American Journal of Public Health, 97*(9), 1671–1676.

Dyer, C. B., Toronjo, C., Cunningham, M., Festa, N. A., Pavlik, V. N., Hyman, D. J., et al. (2006). The key elements of elder neglect: A survey of adult protective service workers. *Journal of Elder Abuse & Neglect, 17*(4), 1–10.

Eisikovits, Z., Koren, C., & Band-Winterstein, T. (2013). The social construction of social problems: The case of elder abuse and neglect. *International Psychogeriatrics* (Special Issue), *25*(8), 1291–1298.

Elder Justice Act. (2010). Retrived from http://www.nlrc.aoa.gov/Legal_Issues/Elder_Abuse/Elder_Justice_Act.aspx

Folstein, M. F., Folstein, S. E., & 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*, 189–198.

Franzini, L., & Dyer, C. B. (2008). Healthcare costs and utilization of vulnerable elderly people reported to adult protective services for self-neglect. *Journal of the American Geriatrics Society, 56*(4), 667–676.

Gibbons, S. (2009). Theory synthesis for self-neglect: A health and social phenomenon. *Nursing Research, 58*(3), 194–200.

Gibbons, S., Lauder, W., & Ludwick, R. (2006). Self-neglect: A proposed new NANDA diagnosis. *International Journal of Nursing Terminologies and Classifications, 17*(1), 10–18.

Gregory, C., Halliday, G., Hodges, J., & Snowdon, J. (2011). Living in squalor: Neuropsychological function, emotional processing and squalor perception in patients found living in squalor. *International Psychogeriatrics, 23*(5), 724–731.

Gunstone, S. (2003). Risk assessment and management of patients whom self-neglect: A 'grey area' for mental health workers. *Journal of Psychiatric and Mental Health Nursing, 10*(3), 287–296.

Harnett, P. J., & Greaney, A. M. (2008). Operationalizing autonomy: Solutions for mental health nursing practice. *Journal of Psychiatric and Mental Health Nursing, 15*(1), 2–9.

Health Service Executive (2012). *Policy and procedures for responding to allegations of extreme self-neglect*. HSE, Dublin.

Health Service Executive. (2013). *Open your eyes there is no excuse for elder abuse*. Dublin, Ireland: Author.

Health Service Executive. (2014a). *Open your eyes there is no excuse for elder abuse*. Dublin, Ireland: Author.

Health Service Executive. (2014b). *Safeguarding vulnerable persons at risk of Abuse: National policy and procedures*. Dublin, Ireland: HSE, Social Care Division.

Hildebrand, C., Taylor, M., & Bradway, C. (2013). Elder self-neglect: The failure of coping because of cognitive and functional impairments. *Journal of the American Association of Nurse Practitioners*, *26*(8), 452–462.

Iris, M., Ridings, J. W., & Conrad, K. J. (2010). The development of a conceptual model for understanding elder self-neglect. *The Gerontologist, 50*(3), 303–315.

Kutame, M. M. (2008). *Understanding self-neglect from the older person's perspective*. ProQuest Information & Learning, US. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2008-99011-293&site=ehost-live Available from EBSCOhost psyh database

Lachs, M. S., Williams, C. S., O'Brien, S., & Pillemer, K. A. (2002). Adult protective service use and nursing home placement. *The Gerontologist, 42*(6), 734–739.

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

Lauder, W., Anderson, I., & Barclay, A. (2005). Housing and self-neglect: The responses of health, social care and environmental health agencies. *Journal of Interprofessional Care, 19*(4), 317–325.

Lauder, W., & Roxburgh, M. (2012). Self-neglect consultation rates and comorbidities in primary care. *International Journal of Nursing Practice, 18*(5), 454–461.

Lauder, W., Roxburgh, M., Harris, J., & 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*(5), 447–454.

Lee, M., & Kropf, N. P. (2013). Capacity Evaluation Screen—Social Work (CES-SW): Development of a brief instrument. *Journal of Social Service Research, 39*(4), 1–9.

Linzer, N. (2004). An ethical dilemma in elder abuse. *Journal of Gerontological Social Work, 43*(2–3), 165–173.

MacLeod, H., & Stadnyk, R. L. (2015). Risk: 'I know it when I see it': How health and social practitioners defined and evaluated living at risk among community-dwelling older adults. *Health, Risk & Society*, *17*(1), 46–63.

Mardan, H., Jaehnichen, G., & Hamid, T. A. (2014). Is self neglect associated with the emotional and financial abuse in community-dueling? *IOSR Journal of Nursing and Health Science (IOSR-JNHS), 3*(3), 51–56.

McDermott, S. (2008). The devil is in the details: Self-neglect in Australia. *Journal of Elder Abuse & Neglect, 20*(3), 231–250.

McDermott, S. (2010). Professional judgements of risk and capacity in situations of self-neglect among older people. *Ageing and Society, 30*(06), 1055–1072.

McMillan, D., & Shaw, P. (1966). Senile breakdown in standards of personal and environmental cleanliness. *British Medical Journal, 2*(5521), 1032–1037.

Naik, A. D., Teal, C. R., Pavlik, V. N., Dyer, C. B., & McCullough, L. B. (2008). Conceptual challenges and practical approaches to screening capacity for self-care and protection in vulnerable older adults. *Journal of the American Geriatrics Society, 56*, S266–S270.

Nursing and Midwifery Board of Ireland. (2014). *Code of professional conduct and ethics for registered nurses and registered midwifes.* Dublin: Nursing & Midwifery Board of Ireland.

O'Brien, J. G. (2011). Self-neglect in old age. *Aging Health, 7*(4), 573–581.

O'Connell, Y. J. (2015). Home care nurses' experiences with and perceptions of elder self-neglect. *Home Healthcare Now, 33*(1), 31–38.

O'Donnell, D., Treacy, M. P., Fealy, G., Lyons, I., Phelan, A., Lafferty, A., et al. (2012). *Managing elder abuse in Ireland: The senior case worker's experience*. Dublin, Ireland: UCD.

Ohio Department of Job and Family Services. (2013). *Adult protective services protocol 2013.* Retrived from http://jfs.ohio.gov/OFC/APSProtocol2013.stm

Patronek, G. J., & Nathanson, J. N. (2009). A theoretical perspective to inform assessment and treatment strategies for animal hoarders. *Clinical Psychology Review, 29*(3), 274–281.

Paveza, G., VandeWeerd, C., & Laumann, E. (2008). Elder self-neglect: A discussion of a social typology. *Journal of the American Geriatrics Society, 56*(Suppl 2), S271–S275.

Pavlou, M., & Lachs, M. (2006). Could self-neglect in older adults be a geriatric syndrome? *Journal of the American Geriatrics Society, 54*(5), 831–842.

Pickens, S. L. (2012). *Assessment of executive function before and after vitamin D replacement in vulnerable adults who self-neglect* (January 1, 2012). Paper presented at the meeting of the Texas Medical Center Dissertations, (via ProQuest). Paper AAI3528769. University of Texas School of Nursing, Houston, US. Retrived from http://digitalcommons.library.tmc.edu/dissertations/AAI3528769

Pickens, S., Ostwald, S. K., Pace, K. M., Diamond, P., Burnett, J., & Dyer, C. B. (2013). Assessing dimensions of executive function in community-dwelling older adults with self-neglect. *Clinical Nursing Studies, 2*(1). Retrieved from http://www.sciedupress.com/journal/index.php/cns/article/view/2354

Post, F. (1982). Functional disorders. In R. Levy & F. Post (Eds.), *The psychiatry of late life* (pp. 180–181). Oxford, UK: Blackwell Scientific Publications.

Poythress, E. L., Burnett, J., Naik, A. D., Pickens, S., & Dyer, C. B. (2006). Severe self-neglect: An epidemiological and historical perspective. *Journal of Elder Abuse & Neglect, 18*(4), 5–12.

Reyes-Ortiz, C. A., Burnett, J., Flores, D. V., Halphen, J. M., & Dyer, C. B. (2014). Medical implications of elder abuse: Self-neglect. *Clinics in Geriatric Medicine, 30*(4), 807–823.

Sheikh, J. I., & Yesavage, J. A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontologist, 5*(1/2), 165–173.

Snowdon, J., Halliday, G., & Banerjee, S. (2013). Severe domestic squalor. *Psychiatry, Psychology and Law, 20*(1), 152–155.

Teaster, P. B., Dugar, T., Mendiondo, M., Abner, E. L., Cecil, K. A., & Otto, J. M. (2006). *The 2004 survey of adult protective services: Abuse of adults 60 years of age and older*. Washington, DC: The National Centre on Elder Abuse. Retrieved from http://www.ncea.aoa.gov/Resources/Publication/docs/2-14-06_FINAL_60_REPORT.pdf

White, W. (2014). Elder self-neglect and adult protective services: Ohio needs to do more. *Journal of Law and Health, 27*(107), 130.

Working Group on Elder Abuse. (2002). *Protecting our future.* Dublin, Ireland: Stationery Office.