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Self-neglect in older populations: A description and analysis of current approaches

Abstract

Self-neglect in old age has severe effects on a person's health and quality of life, and poses diverse challenges for primary caregivers and the community. The authors provide a narrative overview of the literature on self-neglect and summarised what is known to date about the main approaches for describing self-neglect, the factors that contribute to self-neglect, and the interventions that have been attempted. We found that answering the question about what factors led people into a state of self-neglect was extremely complex since many studies described a variety of interlinked factors, some of which are socio-cultural and others, medical. Our analysis suggested a need for a consolidated approach that focusses instead on the vulnerabilities affecting an older person, and the factors which can improve resilience to adversity. Tackling vulnerability and resilience may hold the keys to successful multi-disciplinary and person-centred management of self-neglect in older age.

Keywords:

Self-neglect, old age, resilience, vulnerability, social support

Introduction

Self-neglect in general has severe effects on health, quality of life, and public health consequences. Substance abuse, alcoholism, psychotic disorders, depression and dementia are all associated with self-neglect (Iris, Ridings, & Conrad, 2010). Quality of life suffers because of functional impairments that compromise the ability to fulfil activities of daily living (ADL) and instrumental activities of daily living (IADL) necessary for a functional life (Kutame, 2007). Hoarding behaviour and unsanitary conditions that self-neglecters live in can produce public health problems (Reyes-Ortiz, 2001).

Research on self-neglect is dominated by a large number of unclarified questions, largely related to the wide range of perspectives held by the many and varied actors who are involved in managing cases of self-neglect. This constellation may include the affected persons, their neighbours, family members, landlords, care personnel, social workers, physicians, researchers and policymakers. Consequently, there is a lack of general clarity concerning the naming of the phenomenon. Early studies sometimes preferred titles like “social breakdown syndrome” (Radebaugh, Hooper, & Gruenberg, 1987) or “senile breakdown” (McMillan & Shaw, 1966), while other authors utilised self-neglect and the so-called Diogenes Syndrome interchangeably (see Amanullah, Oomman, & Datta, 2009). In addition, the denomination of the phenomenon differs depending on country, culture or language (Table 1).

There are also debates about whether self-neglect is a form of elder abuse or not. In the US, this can vary from state to state and each jurisdiction might use different definitions (Braye, Orr, & Preston-Shoot, 2011; Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly, 2007). The World Health Organisation’s “World Report on Ageing and Health” (WHO, 2015) does not include self-neglect as a form of elder abuse. Conflicting opinions about an individual’s autonomy and of the surrounding community’s obligation or right to intervene can reinforce

this lack of clarity. Therefore, there appears to be a spectrum of perceptions about self-neglect that carry different notions of blame or responsibility.

[Table 1 about Here]

The absence of standard definitions to date and the presumably high number of unreported self-neglect cases preclude reproducible prevalence estimates, but there are some indications. According to a study for the National Center on Elder Abuse (Teaster et al., 2007), self-neglect is the most common type of abuse reported to adult protective services in most US states. Findings from Scotland reported that self-neglect cases ranged from 157 to 211 per 100,000 population over a 3-year period (Lauder & Roxburgh, 2012). A retrospective study of public health nurses' caseloads in Ireland suggests a prevalence rate of 142 self-neglect cases per 100,000 population (Day, Mulcahy, & Leahy-Warren, 2016). There are contradictory findings with regard to self-neglect's risk factors and its prevalence among certain sociodemographic groups. For example, Lauder & Roxburgh (2012) discovered that more males were reported as self-neglecting and Dong, Simon, & Evans (2012b) showed that male African American older adults have a higher prevalence (13.2%) of self-neglect than their white counterparts (2.4%). In contrast, Dong, Simon & Evans (2010) found that older age, women, African-Americans, and those with lower education or lower income were more likely to be reported for self-neglect. Other studies supplied evidence for the existence of cases of self-neglect in non-Western societies in settings as diverse as India (Nayak, Gopinath, Kini, & Kumar, 2015), South Korea (Lee & Kim, 2014) and Malaysia (Mardan, Hamid, Redzuan, & Ibrahim, 2014).

It seems thus, that self-neglect is a growing epidemic that could possibly affect significant numbers of people all across the globe and can occur across various socioeconomic or cultural backgrounds. At the same time, self-neglect remains hard to

understand for both lay and health professional audiences (Dong 2017). This is problematic as the syndrome has profound health, public and social policy implications for an ageing society. Even though the differences in the legal definitions of self-neglect in many countries makes it difficult to arrive at generalisable solutions, the literature suggests person-centred interventions carried out by interdisciplinary teams as potentially having the most positive outcomes (Day, McCarthy, & Leahy-Warren, 2011). However, the time needed to establish trusting relationships often exceeds what might be reasonably expected of care professionals (McDermott, 2011). In addition, self-neglect presents a variety of complex medical, medico-legal, and ethical challenges to health and social workers of all types, which is why further training for staff members is increasingly needed (Braye, Orr, & Preston-Shoot, 2014).

Methods

The goal of this research was to conduct a narrative overview (Green, Johnson, & Adams, 2006) of the literature on self-neglect in order to identify the gaps presented by current approaches and definitions of self-neglect in older people, with a secondary objective to advance the classification of both the aetiology of self-neglect and thus also, the range of treatments and interventions for self-neglect in older people. The authors summarised what is known to date about the main approaches for describing self-neglect, the description of factors that contribute to self-neglect and the interventions that have been attempted to date. This was accompanied by a synthetic analysis of any gaps uncovered in this review that affected the current understanding and conceptualisation of the aetiology of self-neglect, and the deployment of interventions for self-neglecting older people. The databases MEDLINE (PubMed) and Google Scholar were searched using combinations of the search terms “self-neglect”, “Diogenes syndrome”, “Squalor Syndrome”, “elderly” or “old”, and “aetiology” or “factors” or “interventions”, with publication date (2000/01/01 to 2016/12/31) and language (English) as activated filters. In total, 276 titles and abstracts were obtained from the search and evaluated (Figure 1).

These titles and abstracts were then reviewed for duplication and pertinence. A study's pertinence was assessed through its abstract. The key inclusion criteria were that a study focussed on self-neglect and not on other forms of abuse, and that it related in full or in part to older people. Articles that did not present any findings relevant to the definition, factors or interventions for self-neglect were excluded. For example, papers which merely listed self-neglect as an outcome or as a co-factor of certain mental illnesses, but did not contribute any findings relevant to our research question, were not included.

196 papers were excluded, while full texts were obtained for 80 papers (approximately 30% of the abstracts). These were hand searched for cross references to include published special reports, grey literature, frequently cited older studies that were published before 2000, and other relevant papers. These manual searches also revealed non-English-language articles, which were then included subject to the language expertise available at the WHO Kobe Centre (see limitations section). In total, 90 articles were included as being relevant with respect to their discussion of the definition of the term self-neglect, their methodological approaches, described factors or interventions (Figure 1).

Out of these 90 publications, 42 were quantitative studies, 11 were qualitative studies, while 6 studies followed a mixed methods design and 13 articles were smaller (qualitative) case studies of four or less cases (mostly a single case). 18 publications were literature reviews (including 3 systematic reviews) or encompassed conceptual and theoretical work.

[Figure 1 about Here]

Results

Main theoretical approaches and definitions

To date, no generally accepted overarching explanatory model of self-neglect has been developed (Braye et al., 2014) and many publications (Lauder, Anderson, & Barclay, 2002;

Burnett, Pickens, Prati, Aung, & Dyer, 2006; Braye et al., 2011) distinguish the literature on self-neglect very broadly into two kinds of approaches (Table 2). Studies of the first category follow a medical perspective and mainly treat self-neglect as a health issue or as a special syndrome. In contrast, studies challenging the medical model try to conceptualise self-neglect by discussing fundamental questions concerning the sociocultural background of self-neglect and thus, who or what services are ideally placed to respond with solutions (Lauder et al., 2002). They question certain assumptions taken by medical approaches to the issue and emphasise the social aspects and dynamics of self-neglect. Iris et al. (2010) identified a similar distinction within self-neglect literature and also broadly distinguished the literature into psycho-medical approaches on the one hand, and sociocultural approaches on the other.

Approaches that strictly follow the medical model are prone to overlook or even ignore underlying biographical factors, or the deliberate choices that self-neglecting persons make. On the other hand, critical approaches that define self-neglect as socially constructed or even as a natural part of a human being's life cycle may underestimate the contribution of underlying medical conditions. Many studies thus try to reconcile both of these perspectives and attempt to assess medical as well as environmental factors leading to self-neglect. Examples of such assessment tools will be presented in later parts of this paper (Day & McCarthy, 2016; Dyer et al., 2006; Iris, Conrad, & Ridings, 2014). However, the difficulties of locating an agreed definition for self-neglect illustrates the continuing significance of these two major contrasting perspectives. That is to say, arriving at a definition of self-neglect poses a first major problem, because the term "can be redefined based on the presence or absence of caregivers, the presence or absence of mental illness, the capacity to accept or refuse services or treatment, and by cultural or community norms" (Kutame, 2007, p. 8). Early definitions of the phenomenon tried to list common features of persons labelled as self-neglecters (Clark, Mankikar, & Gray, 1975). The high prevalence of these indicators of self-neglect then led to the conceptualisation of self-neglect as a medical or geriatric syndrome in the 2000s (Pavlou

& Lachs, 2006; Naik, Burnett, Pickens-Pace, & Dyer, 2008). However, the conception of self-neglect as a geriatric syndrome contains the risks of ignoring factors such as individual choice. It may also overestimate the contribution of medical conditions while overlooking underlying social factors, and excludes self-neglect cases in younger populations. In this regard, Lauder, Roxburgh, Harris, & Law (2009) underlined self-neglect as a rather loose term that is used to describe a wide range of behaviours, lifestyles and associated medical conditions.

[Table 2 about Here]

Another point of contention is whether to distinguish between intentional and unintentional self-neglect, which seeks to differentiate between whether a self-neglecting person actively decided on actions that are perceived as self-neglecting or if the person unintentionally ended up in their situation (Gibbons, Lauder, & Ludwick, 2006). Correspondingly, Reyes-Ortiz (2001) differentiates between a primary and a secondary Diogenes syndrome. While the former is not associated with any underlying medical conditions, the latter is said to be related to mental illnesses and disorders, dementia and alcoholism. Therefore, many studies acknowledge a division between those cases in which people actively chose to live in self-neglecting conditions and those cases where illnesses or impairments forced individuals into self-neglecting behaviours. The American National Center on Elder Abuse even explicitly excludes cases “in which a mentally competent older person, who understands the consequences of his/her decisions, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety” (NCEA, 2016, para. 2). However, not all definitions leave out intentional self-neglecters (Iris et al., 2014), because the distinction between intentional and unintentional self-neglect is directly related to ethical questions around the right or obligation to intervene. This includes questions about whether

mentally impaired persons possess the capacity to decide to opt out of society and if a possible intervention constituted a violation of the person's autonomy and rights.

Given the wide range of conditions that are covered by the term self-neglect, some authors attempted to define the core characteristics of most self-neglect cases and thus to work out more general definitions. For example, Gibbons et al. (2006) defined self-neglect as "the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglector and perhaps even to their community" (p. 16). However, while focusing on the lack of sufficient self-care practices helps to explain some elements or types of self-neglect, relying only on self-care theory to explain all aspects of self-neglect is too narrow (Lauder, 2001). For example, issues of choice or responsibility, and possible cultural differences can be marginalised although they are central to understanding the situation of a self-neglecting person. It is also important to note that the perspective on possible self-care deficits is identified by external agents and thus in large parts relies on an externally formulated subjective judgement that is based on certain norms of tidiness and hygiene (Lauder, 1999). Some authors even question the feasibility of measuring self-neglect because they view self-neglect as socially constructed, and not as an objectively measurable symptom (Bozinovski, 1998). Conceptualising self-neglect as a social construction can eventually lead to questioning the notion of "self-neglect" itself, as the term can evoke blame being attached to the affected persons and even make them the target of social stigma (Bozinovski, 1998). Lustbader even regarded self-neglect as a natural part of a human being's life cycle and remarked that "the penchant for self-destruction is part of the human condition" (NCPEA Education Committee, 2008, p. 21).

In contrast, other authors were critical of viewing self-neglect as socially constructed because significant health risks could be overlooked and the concept of self-determination, for example, could be used inappropriately as a reason for leaving older people alone without

intervention in possibly life-threatening situations (Bergeron, 2006; Braye et al., 2011, p. 30; McDermott, 2011). Yet, Lauder et al. (2002) defended the value of sociocultural approaches, because these would present the self-neglecting person as an active actor who is still interacting with his or her environment and thus, reacting to perceived threats to his or her identity. A number of qualitative studies (Kutame, 2007; Band-Winterstein, Doron, & Naim, 2012; Lien et al., 2016) suggested how sociocultural approaches can offer new possibilities for intervention measures; these studies demonstrate how a self-neglector could be helped to regain the necessary coping mechanisms for living.

The factors that lead to self-neglect

The factors that can lead to self-neglect are varied and diverse. The Elder Self-Neglect (ESN) model elaborated by Iris et al. (2010) encompasses internal (physical and psychosocial) as well as external (environmental) factors for self-neglect in old age. The list of factors was determined following brainstorming sessions with twenty experts, who together with an additional thirty practitioners then ranked the factors by perceived levels of importance for self-neglect. The ESN model posits that it is not only physical and mental health factors that are crucial for self-neglect but that environmental factors could also be contributors to the emergence of self-neglect by an individual. According to the model, internal factors comprise mental health, physical health, social networks and personal endangerment. Mental health issues are usually defined as the most important factors and included substance abuse, alcoholism, psychotic disorders, depression and dementia. Dyer et al. (2007) frame their model of self-neglect around *executive dysfunction* – i.e., the inability to order and sequence tasks that are associated with activities of daily living (ADL) impairment. Following a cross-sectional study of over 500 patients in a geriatric clinic in Houston, Texas, executive dysfunction was identified as a common result of various aetiologies like diabetes mellitus, cerebrovascular accidents, dementia or depression. This impaired executive functioning would interfere with an older person's ability to cope with physical disabilities, which in turn

again could exacerbate functional impairments (see also Hildebrand, Taylor, & Bradway, 2014). Following this logic, physical impairments to execute ADLs and IADLs are particularly associated with self-neglect when combined with insufficient or declining coping skills or unsuccessful adaptations to physical deficits, as these factors together may lead to the formation of a disproportionate disability for the performance of daily tasks. The conceptual approach of Paveza, Vandeweerd, & Laumann (2008) follows a similar approach where it details the effects of internal vulnerabilities and external risks. Many conceptualisations (e.g. Iris et al., 2010) further suggest that all of these factors – internal as well as external – are interlinked to each other, reaffirming the complexity of self-neglect's aetiology.

The complex relations between mental and physical health issues on the one hand and self-neglect on the other hand were highlighted by the findings of several quantitative studies. Dong et al. (2010a) analysed data from 5519 participants in the Chicago Health and Aging Project and found that decline in executive function was associated with both reported and confirmed self-neglect. Another publication using data from the same project also revealed an association between lower levels of physical function and higher self-neglect severity (Dong et al., 2010b). A study of 3159 Chinese older adults residing in the greater Chicago area also associated lower levels of cognitive, physical, and psychological health with greater risk to self-neglect of varying severities (Dong & Simon, 2015a). Aung, Burnett, Smith, & Dyer (2006) detected malnutrition (Vitamin D deficiency) and subsequent impaired physical performance in 16 of 44 self-neglecting persons. Other findings of a study involving 91 persons living in squalor and receiving special cleaning services suggested that mental disorders could be especially prevalent in self-neglecting persons under 65 years old, while older self-neglecters were less likely to suffer from mental disorders, but were more often afflicted by physical impairments (Halliday, Banerjee, Philpot, & Macdonald, 2000).

However, still other studies challenge these associations and questioned whether an older person “may neglect his or her needs because of cognitive problems, or, conversely, [if]

poor self-care may lead to mental decline” (Hildebrand et al., 2014, p. 456). Pickens, Naik, Burnett, Gleason, & Dyer (2007) found that self-neglecting older people were more likely to fail the Kohlman Evaluation of Living Skills (KELS) than a control group, even when they had no cognitive impairments – a result that challenges the notion of executive dysfunction. A number of qualitative studies further question the dominant role accorded to cognitive impairments and mental health issues. Qualitative interviews with 69 cognitively intact, self-neglecting older adults revealed the significance of traumatic personal experiences – such as losses and separations (29%) or experiences of physical violence or sexual abuse (19%) – as well as problematic living conditions or behaviour patterns – such as living in financial instability (23%), dealing with lifelong mental illness (16%), having mistrust of people (13%) or substance abuse (13%) (Lien et al., 2016).

This conceptualisation of self-neglect as part of a person’s overall life course and not as a general issue of old age is also supported by another qualitative study of 16 self-neglecting older persons in Israel (Band-Winterstein et al., 2012). Similarly, Bozinovski (1998) conducted qualitative interviews with 30 self-neglecting persons and reported experiences of abandonment and abuse, as well as possession of fears of being encroached and controlled by others. Such experiences and character traits could further lead to reluctance to receive help, although other studies suggested the reason for help-avoidance was based on personal pride or shame (Kutame, 2007; Day et al., 2011). Lauder et al. (2009) described cases of self-neglect that possibly derived from exceptionally chaotic living environments and unstable biographies that were dominated by a theme of loss. However, even when a general refusal of help could not be observed, a widespread suspicion directed towards statutory services was common, while voluntary services were largely accepted and trusted. Such personality traits could be further amplified through the manifold effects of living with health conditions like dementia and depression (Kutame, 2007). For example, Nayak et al. (2015)

observed that even the symptoms of potentially serious illness can act as a stress factor which can exacerbate or trigger self-neglect.

External or environmental factors are an additional category of factors that can lead to self-neglect. The aforementioned Elder Self-Neglect model by Iris et al. (2010) defines physical living conditions, financial issues and personal living conditions as external factors, while the lack of social support is classified as an internal factor. In contrast, Dyer et al. (2007) interpreted the lack of social support as an extrinsic social issue that can result in inadequate access to support/health services and therefore exacerbates health issues (which are construed as internal factors). There is evidence from qualitative as well as quantitative studies that supports the importance of such external factors, including the role of social networks. For example, Dong et al. (2012b) reported that even when self-neglect occurred across various sociodemographic and socioeconomic strata, a higher prevalence was reported in less-educated populations. A study of older adults living in the community that included 91 self-neglecters out of 2161 total persons reported a strong association between low income and self-neglect (Abrams, Lachs, McAvay, Keohane, & Bruce, 2002). Similarly, qualitative studies connected self-neglect with general patterns of social exclusion (Lauder et al., 2009) and not only with the lack of economic resources, but also with the lack of access to public social services (Kutame, 2007). An analysis of reported self-neglect cases to Adult Protective Services (APS) in Texas (Choi, Kim, & Asseff, 2009) supports this association between low socioeconomic status and the lack of access to formal healthcare programs. However, an early pioneering work on self-neglect (Clark et al., 1975) also detected self-neglect in well-educated populations with high housing standards which again demonstrates how widely the phenomenon may be discovered in different socio-economic settings.

Social networks may be a key factor in cases of self-neglect. A study of 91 cases of self-neglecters found that the self-neglecters possessed significantly decreased social networks, independent of other variables such as age, gender, race, and socio-economic status

(Burnett et al., 2006). Self-neglecters in this study were mostly living in one-person households, had less contact with family, friends or neighbours, and participated less in religious activities. A study by Dong et al. (2010) used data from 9056 participants of the Chicago Health and Aging Project, including a subset of 1812 reported self-neglect cases, and found that lower levels of social networks and social engagement were significantly and independently associated with an increased risk of self-neglect. A survey conducted for the Japanese government (Naikakufu, 2011) in which social workers were asked about known trigger points for observed self-neglecting behaviours reported similar findings. The participants reported that in 27.5% of the cases, self-neglect had worsened after experiences of loss of a close relationship, and that social isolation had been a trigger in 25.4% of the cases. Interviews with case workers in Ireland also confirmed occurrences of self-neglecting behaviour in cases of older people who were living in social isolation (Day et al., 2011). In contrast, a secondary study of 704 self-neglect cases in San Francisco did not find any association between self-neglect and social isolation (Spensley, 2008), while a qualitative study by Kutame (2007) indicated that several self-neglecters in their study perceived themselves to be still helpful to others, even though they lacked social networks.

The contradictions within findings with regard to the factors that lead to self-neglect, form key issues that mark the current state of research on self-neglect. On the one hand, the differences in the results could be due to differing study methodologies. For example, qualitative interviews with self-neglecting persons will mostly likely reveal different aspects of self-neglect compared to quantitative studies focussed on disease patterns of patients within a geriatric clinic setting. On the other hand, the wide range of factors associated or not associated with self-neglect shows the broad spectrum that makes up self-neglect cases. Self-neglect affects people with differences in age, gender, mental health, physical health, sociocultural background and socioeconomic status. In this regard, articulating adequate general intervention strategies will certainly not be easy.

Exploring current interventions, and the legal and ethical frameworks that interventions need to work within

Similar to the wide range of definitions and concepts of self-neglect, policies and legal procedures with respect to possible interventions varied from country to country, and very often, even within countries. Accordingly, most US states defined self-neglect as a form of elder abuse, but at the same time employed different procedures on how to tackle the issue (Teaster et al., 2007). For example, Texas state law defined self-neglect as a form of physical neglect and requires all citizens to report cases of self-neglect to Adult Protection Services (Franzini & Dyer, 2008), while the state of Connecticut differentiated between mandatory reporting of self-neglect by licensed health care providers and non-mandatory reports through family members or neighbours (Abrams et al., 2002; see also Braye et al., 2011, pp. 39–47). In contrast, in the UK, self-neglect had not been placed under the safeguarding umbrella until the enactment of the Care Act 2014. Following the act, all local authorities are now required to set up adults safeguarding boards, make enquiries if a person is experiencing, or at risk of, abuse or neglect, and then to take the necessary actions (Department of Health & Social Care, 2018).

However, the practical implementation of legal frameworks encounters several problematic issues. Detecting cases of self-neglect poses the first major issue, since “intervention usually does not occur at the request of the individuals themselves” (Cipriani, Lucetti, Vedovello, & Nuti, 2012, p. 457). The discovery of self-neglect cases thus, mainly happens if a case is reported or comes up during assessment. To avoid the risk of subjective judgements, a few tools have been developed to identify self-neglect, such as the Elder Self-Neglect Assessment form (Iris et al., 2014) or the CREST Self-Neglect Severity Scale (Dyer et al., 2006). However, Day & McCarthy (2016), felt that most of these tools failed to capture the multidimensional and complex nature of many self-neglect cases. Drawing upon previous qualitative research, a thorough literature review and the experience of eight purposely

selected experts, Day and McCarthy developed and successfully field tested a self-neglect measurement instrument called SN-37. This instrument details 37 items within five categories (environment, social networks, emotional and behavioural liability, health avoidance, and self-determinism) to determine whether or not a person may be self-neglecting (Day & McCarthy, 2016). However, further testing of the instrument is still needed.

Yet, the successful identification of a self-neglect case does not necessarily lead to effective intervention and treatment of accompanying health and social issues. Legal frameworks or ethical codes of care in many countries stress the need to respect an individual's autonomy and personal choices. Thus, unless it is decided that they are lacking mental capacity, self-neglecters have the right to refuse help from caregivers. This opens up a conflict between the state's or a caregiver's duty to intervene, care and prevent potential public health hazards on the one hand; with an individual's right to live a self-determined life on the other hand. A study from Australia utilising in-depth qualitative interviews with eighteen professionals working with self-neglect and squalor in the community described the practical consequences of this conflict (McDermott, 2011). McDermott (2011) found that professionals from health-focused organisations were more likely to respect the decisions of self-neglecting persons as they were still largely viewed as possessing decision-making capacity. However, professionals from social care organisations, such as assistance for housing organisations, described the need to intervene to prevent harm from spreading to the surrounding community. The question of capacity and the surrounding difficulties of assessing capacity in practice has therefore, been given broad attention in many papers on self-neglect (Braye et al., 2011, pp. 26–38).

Treatment of self-neglect and related health issues in cases of self-neglecting persons encounter several other challenges. Generally, self-neglect is associated with higher hospitalization rates (Dong, Simon, & Evans, 2012a) and self-neglecters have a higher risk of readmission to a hospital within 30 days after discharge following first hospitalisation (Dong

& Simon, 2015b). However, this might be due to the fact that many self-neglecting persons are typically not accessible to healthcare personnel until diagnosed as seriously ill, and are thereby suffering from more severe health problems (Pavlou & Lachs, 2008). A study of 131 self-neglect cases (with an equal size control group) showed that once self-neglecting individuals were brought into the formal healthcare system, their healthcare costs were not necessarily higher than those of other patients with similar diagnoses (Franzini & Dyer, 2008). Yet, there are persuasive arguments that simply treating a self-neglector's medical condition in a hospital is not enough. Instead intervention strategies should be more sensitive, less invasive, focussed on the self-neglecting persons' articulated needs and life course biographies, and should also emphasise the importance of the social environment of the affected persons (Bozinovski, 1998; Kutame, 2007; Band-Winterstein et al., 2012).

Day and colleagues, who have studied self-neglect in Ireland, champion person-centred measures. A study based on qualitative interviews with 7 case workers stressed the need for multi-agency approaches that included individually tailored responses which meet the specific and varied needs of different self-neglecters (Day et al., 2011). A study of 8 self-neglecting older adults (Day, McCarthy, & Leahy-Warren, 2013) suggested that decisions of self-neglecters to live in this way should be respected. Some papers also suggest dividing self-neglecters into sub-types in order to better target the most appropriate intervention strategy (Amanullah et al., 2009; Reyes-Ortiz, Burnett, Flores, Halphen, & Dyer, 2014) amidst the large diversity of self-neglecters. Such categorisations for example, could be based on a self-neglecting person's attitude towards receiving help from others or on the presence of family members living nearby.

Finding appropriate ways to approach self-neglecting older people in order to investigate their situation or to develop assistance strategies (with their consent) is a key challenge, and studies highlighted the efficacy of persuasion or negotiation tactics that could be used to build up trusting relationships with self-neglecting persons (Smith, Lo, & Aronson,

2013; Torke & Sachs, 2008). For example, McDermott's (2011) qualitative study suggested that a viable strategy could be to gradually build up relationships of trust with self-neglecting persons, while simultaneously negotiating adoption of better personal care practices, such as attending to home cleaning activities or else improving personal hygiene practices. Braye et al. (2014) who conducted semi-structured interviews with 20 safeguarding and social care managers, 42 practitioners and 29 service-users also focused on building relationships between caregivers and service-users. This study recommended creative and flexible interventions structured around a person's life course which respond appropriately to their individual needs. Such an approach would have to incorporate multiple agencies with interdisciplinary collaboration, ensure balanced professional assessments across health, social care and welfare sectors, and would also need to be responsive to varying legal environments. Therefore, instead of recommending model solutions, the literature was mainly suggesting the need for a person-centred approach delivered by multidisciplinary teams, which would tailor individualised care plans to treat medical conditions, arrange the living environment and strengthen social support for self-neglecting older persons. Such approaches should additionally incorporate other critical considerations, such as informed consent, the right to privacy and an understanding of what constitutes the best interests of the self-neglector. Adopting an integrated approach facilitates interventions to achieve key ethical outcomes such as beneficence, non-maleficence and autonomy (Day, Leahy-Warren, & McCarthy, 2016).

However, these strategies are quite time-intensive and would require additional education and training programmes for care personnel and other involved actors in order to develop the appropriate management competencies, while still remaining compliant with the legal framework of a given setting (Day, Leahy-Warren, & McCarthy, 2013). Qualitative interviews with 22 experienced nurses in Israel revealed confusion and ambiguity among these nurses with regard to how to deal with cases of self-neglect, accentuating the urgent

need for further training (Band-Winterstein, 2016). Similarly, 77% of 55 responding safeguarding agencies in England said that there was either no training at all, or at least no specific training available for issues of self-neglect (Braye et al., 2014).

Discussion

This review summarised key findings about self-neglect, alongside detailing several problematic aspects of the current state of research. In this regard, the review probably highlighted more questions than provided answers. Answering the question about what factors led people into a state of self-neglect was, for example, not trivial, but revealed a complexity of interlinked factors. The particular role of mental health issues and physical impairments was underlined through the findings of quantitative studies, whereas the results of qualitative studies articulated the need to incorporate environmental as well as biographical factors in order to understand and help a self-neglector. However, contradictions remain and research into the interrelations between these factors is still needed. This includes, for example, questions concerning the reciprocity of the relationship between physical impairments and mental health issues, or of the relationship between environmental (external) and internal factors in self-neglect. Furthermore, it remains difficult to distinguish between indicators of self-neglect from aetiologies that led to self-neglect. For example, is living in squalor just an indicator of self-neglect or does it worsen issues of physical health and increase tendencies to self-neglect?

Secondly, the results of this narrative overview suggest that research into self-neglect is still restricted by substantial methodological limitations. For example, most studies understandably relied on cases of self-neglect which had been reported to adult protective services or medical institutions. However, by the time they are reported, these cases could represent sufferers who are already at the more severe end of the self-neglecting spectrum, potentially leaving many more less severe cases of self-neglect undiscovered. These might be harder to detect or initiate contact and are thus usually excluded from research. Qualitative in-

depth interviews with 10 younger, rather non-stereotypical cases of self-neglecters by Lauder et al. (2009) also confirmed the need for more longitudinal research into how self-neglect could develop over a person's life course and how these developments might be attended to or even controlled earlier in the life course.

Moreover, 17 of 90 included studies, that is roughly 20% of all studies and representing up to 40% of all included quantitative studies, were written by Dong and colleagues and in 14 cases their data was drawn from the Chicago Health and Aging Project. This revealed a lack of diversity, especially with regards to good quality longitudinal studies that captured broad but representative samples. Furthermore, even though Dong and colleagues have generated detailed and well researched findings, this dominance of a developed northern perspective into the field of research for self-neglect underlines the need for more data from other communities or countries. Our review identified only four studies from Asia, two from Australia, one from Latin America, two from Middle East and none from Africa. The majority of studies were thus conducted in North America and Europe with almost all studies from North America having been conducted in the United States. There is a need for more comparative and culturally diverse research within this debate. This paper highlighted the fact that definitions of self-neglect necessarily contain norms and judgements and these will vary according to their respective socio-cultural backgrounds. It would be crucial to see if and how definitions and interpretations of self-neglect might differ depending on language, culture and social norms.

Our analysis suggests that there is a need for a reframed conceptualisation of self-neglect that integrates both medical as well as socio-cultural perspectives of self-neglect. Such a model must address the complex underlying conflicts between the individual's right to live a self-determined and independent life on the one hand, with the surrounding community's standards of health and hygiene on the other hand. In this light, this review is suggesting that discovering generalisable interventions that will fit all types of self-neglecters

will be more unlikely because the term self-neglect describes such a wide range of underlying medical conditions that are also highly dependent on community standards and/or cultural norms for diagnosis. Therefore, we propose reframing self-neglect to represent types of behaviours which results from underlying *vulnerabilities, whatever the origins of those vulnerabilities*. The key here is neither labelling whole populations nor the whole of an individual as vulnerable, but rather to set about distinguishing the different “layers of vulnerability” (Luna, 2014) within a person, that may be contributing to self-neglect. That is to say, self-neglect may not in of itself be a medical condition, but rather a behavioural marker of a layer or accumulated layers of vulnerability(s) that makes self-neglect more likely or possible. Seen in this light, self-neglect becomes a potential contributory factor that can exacerbate mental health issues or functional impairments or else arise as a potential result of these issues. Self-neglect therefore, has two interlinked facets within this line of thinking – as both an outcome and as a contributory factor to decline. Self-neglect thus, functions within a feedback loop (Figure 2). In this context, researching the interrelations between different layers of vulnerabilities (for example, co-terminus existence of poverty, social isolation and physical disability) that can lead to self-neglect, and then understanding how certain self-neglecting behaviours can lead to an acceleration of deteriorating health and social conditions will be of key importance.

[Figure 2 about Here]

In figure 2, we postulate that self-neglect can sit in a negative feedback loop, and that such loops might only be broken when we think about how an individual’s strengths and capacities can be brought to the fore, in order to break a vicious circle. In this light, resilience becomes the mirror image of vulnerability (Kuh, Ben-Shlomo, Lynch, Hallqvist, & Power, 2003) and possibly a key component to escaping a negative spiral. Adversity happens to all

people at some point in their life course. Bonanno (2004) proposed that resilience to potential trauma be defined as “the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as the death of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and physical functioning, as well as the capacity for generative experiences and positive emotions” (pp. 20–21). A key point is that even resilient individuals may experience at least some form of transient stress reaction; however, from a vulnerability perspective, self-neglect might arise when these reactions become long term and/or of great severity, and thus interferes with a person’s ability to continue normal functioning or to lead a meaningful life (Bonanno, Moskowitz, Papa, & Folkman, 2005; Bonanno et al., 2002; Ong, Bergeman, Bisconti, & Wallace, 2006). This leads to the question of how a person’s resilience might be strengthened and when such processes can be initiated. This acknowledges that there are always two common components of resilience, that is, adversity and positive adaptation. A self-neglecting person’s coping mechanisms, the psychological and physical functioning, as well as their environments could become targets for help and support interventions that might boost positive adaptation and arrest or even reverse a trajectory of self-neglect. Potential interventions should be thought of in terms of identifying strengths and capacities within individuals that may be stimulated to encourage more positive adaptations to adverse conditions and/or despair.

Self-neglecting persons can be understood thus, as individuals who have acquired certain layers of vulnerabilities, for example, through poorer personal intrinsic capacities (WHO, 2015, pp. 28–30) or deteriorating social support networks to cope with life-changing events. Thus, living in social isolation might lead to an insufficient response in face of the sudden loss of functional capacity due to a health crisis, while having depressive symptoms or other mental health conditions might lead one to lose the requisite resilience to keep social networks alive or continue the common activities of daily living.

If this line of thinking is correct then the way forward in managing self-neglect, beyond either a psycho-medical or socio-cultural framing of the condition, would involve support and care through multi-disciplinary, person-centred approaches that can minimise or even eliminate an older person's layers of vulnerabilities, while simultaneously strengthening more positive adaptations to adverse conditions, and also concurrently improving an afflicted person's environmental, health and social circumstances.

Limitations

This review has several limitations. Firstly, there was a key methodological problem, centred around whether to include studies published only in the English language or alternatively, those in any language. A pragmatic decision was taken to include studies only in English, German, and Japanese (for which language expertise was available) that were identified after the initial database search through additional hand-searching of the reference lists of included articles. This strategy yielded only two Japanese- or German-language papers, with the remainder being in the English language. Thus a bias towards English-language articles remained. The search was not extended to include non-English equivalents for self-neglect (as listed in Table 1) for those other languages. This may result in a socio-cultural bias in terms of the description of results offered in this paper. It reaffirms the authors' call for more cross-cultural and comparative research on the issue.

Furthermore, although this narrative overview includes the main positions and systematic reviews (Braye et al., 2011; Hildebrand et al., 2014; Pavlou & Lachs, 2006) on self-neglect in English, it raises new questions without providing adequate answers to outstanding problems. The search strategy was designed to be inclusive rather than exclusive in order to capture the diversity of positions on self-neglect, and as a consequence we sought to include any relevant quantitative or qualitative study, without assessment of the quality of these studies. Despite the breadth of the search, this review cannot present a new definition of self-neglect nor can it provide evidence for novel or optimal intervention strategies.

Accordingly, the discussed concept for the reframing of self-neglect needs to be tested and elaborated in further studies which should include the use of both quantitative and qualitative research methods.

Conclusion

A synthesis of the findings from this review suggests that self-neglect might be viewed as a symptom resulting from an existing vulnerability, a combination of several existing vulnerabilities or as behaviour that can increase a person's vulnerability. As such, these vulnerabilities could also function as both aetiology and outcome of the process of self-neglect, within a negative feedback loop. Self-neglect can significantly compromise a person's health and decrease the available lifestyle options. Independent of what factors have led to self-neglecting behaviours, a person might lack the resilience to cope with the life-changing events due to personal or external environmental factors. This can include making (or neglecting to make) decisions leading to bad health, because of lack of knowledge or motivation to do otherwise, as well as the lack of capacity to make decisions that could aid coping with functional decline or stressful events. In this way, even so-called intentional self-neglecters may be described as vulnerable and thus, potentially lacking in resilient coping mechanisms.

Therefore, there may be a need to incorporate the concepts of resilience and vulnerability within any attempts to reframe self-neglect; and this could be a crucial step towards reconciling medical and socio-cultural framings of the issue. In this way, those who are suffering from self-neglect might receive help in a genuinely integrated, person-centred and multi-disciplinary way that values equally both the medical and social perspectives of the issue. Such integrated interventions may also succeed in breaking up negative cycles of increasing vulnerability, by focussing on the elements of resilience, personal capacity and strengths, all of which may be brought to bear to help self-neglecters escape from a negative spiral.

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Tables

Table 1 Examples to illustrate the range of conceptions of self-neglect in different languages. While equivalents for the medical term Diogenes Syndrome are used in all languages, broader public discussions mostly developed around varying established terms in many different countries implying a need for further review

USA/UK	Self-neglect, Senile Breakdown etc.
France	Incurie (“carelessness”)
Germany	Messie-Syndrom (“compulsive hoarding”)
Japan	Kodokushi (“lonely death”), Tojikomori (“Secluding oneself in a room or house”)
Spain	Síndrome de dejadez senil (“senile carelessness syndrome”)

Table 2 Contrasting perspectives of medical and socio-cultural approaches to Self-Neglect

Studies following the medical model ("psychomedical approaches")	Studies challenging the medical model ("sociocultural approaches")
Self-neglect as an illness, as a geriatric syndrome	Self-neglect as socially constructed, dependant on social judgements
Emphasise the importance of mental health issues ("executive dysfunction")	Emphasise factors like social exclusion, poverty, deviant lifestyles
Tendency to medicalise self-neglect (treat and release)	Fear overmedicalisation, but might oversimplify medical issues
Tendency to regard social factors as less important mediating factors	Self-neglecting persons as active actors who interact with their environment and react to perceived threats to their identities

Figures

Figure 1 Image of Article Selection Process

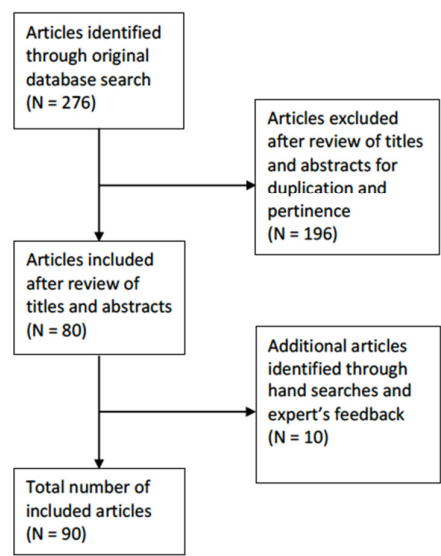


Figure 2 A synthesis of several key concepts in order to present a reframed model of self-neglect

