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Self-Neglect: Development and Evaluation of a Self-Neglect (SN-37) Measurement Instrument

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A B S T R A C T

Self-neglect (SN) is a global phenomenon, largely hidden, poorly defined, and a serious public health issue. It can be intentional or unintentional and depends on the individual's capacity. Creating a safe living environment for self-neglecting adults can present complex ethical challenges. The purpose of this research was to develop and evaluate the psychometric properties of an instrument to measure professional's perceptions of self-neglect. A descriptive cross-sectional design was used in this two-stage study. Stage 1 involved the generation of an item pool (90 items), face and content validity; and pilot testing of the instrument. In stage 2, the questionnaire was posted to a national sample of community health and social care professionals (n = 566) across Ireland, with a 60% response (n = 339). Exploratory factor analysis (EFA) was conducted using scale development guidelines to identify scales and subscales of the instrument. Construct validity was established using EFA. The result was a 37-item SN instrument, composed of five factors: environment, social networks, emotional and behavioural liability, health avoidance, and self-determinism which explained 55.6% of the total variance. Factor loadings were ≥0.40 for all items on each of the five subscales. Cronbach's alpha (α) for four subscales ranged from 0.83 to 0.89 and one subscale was 0.69. The SN-37 can be used not only to measure SN, but also to develop interventions in practice. Further testing of the SN-37 in primary care settings with diverse populations is recommended.

Self-neglect (SN) is frequently described as an older person's inability or unwillingness to provide the goods or services to meet basic needs (Day, 2010). It can be intentional (active neglect) or non-intentional (passive neglect) (Day, 2010). It encompasses a constellation of behaviours, cumulative self-care deficits (Adams & Johnson, 1998; Braye, Orr, & Preston-Shoot, 2014; Reyes-Ortiz, 2001) and environmental neglect (Iris, Ridings, & Conrad, 2010). The term domestic squalor is unique to the Australian context and is applied to households that are extremely cluttered and filthy (Snowdon, Halliday, & Banerjee, 2012). There is an accumulation of items, personal objects, rubbish, excrement and decomposing food and the environment as a result can jeopardise the health and wellbeing of the occupant(s) (Government of South Australia, 2013; Snowdon et al., 2012). Squalor is considered an environmental dimension of SN (Day & McCarthy, 2015). Both domestic squalor and SN are interrelated and conceptualised as the same concept by some researchers (Halliday & Snowdon, 2009; Snowdon et al., 2012). SN can occur across the lifespan in both younger and older people. In addition, SN is largely hidden and often coexists with elder abuse (Bartley, Knight, O'Neill, & O'Brien, 2011; Gunstone, 2003; Health Service Executive, 2013; May-Chahal & Antrobus, 2012).

Definitional issues have created multiple challenges and contributed significantly to a wide disparity in reporting prevalence of SN (Jogerst et al., 2003). Older people's self-care is a multifaceted issue. In the United States (US) SN is included in the definition of elder abuse in many states (Teaster et al., 2006). However Australia, England and Ireland do not include SN as elder abuse (Braye, Orr, & Preston-Shoot, 2013; Department of Health, 2000, 2009; Health Service Executive, 2012; Working Group on Elder Abuse, 2002). The current available prevalence data on SN are limited and in the US it is reported to be 9% (Dong, Simon, Mosqueda, & Evans, 2012) whilst Korea reported a prevalence of 4.1% (Lee & Kim, 2014). Data from primary care General Practitioner caseloads in Scotland suggest that prevalence rates vary from 166 to 211 per 100,000 populations (Lauder & Roxburgh, 2012). This coincides with data from a retrospective review of Community Profile and Health Need Assessments (CPHNA) of Public Health Nurses in Ireland, that suggests a prevalence rate for SN as 142 per 100,000 population (Day, Mulcahy, & Leahy-Warren, 2016). SN cases account for 20% of the referrals received by specialist senior case workers who work specifically with elder abuse services (Health Service Executive, 2014).

Available evidence suggests that SN is associated with multiple medical comorbidities; significantly greater mortality (Dong et al., 2009), hospitalisation; (Dong & Simon, 2015; Dong, Simon, & Evans, 2012b, 2012c); hospice use (Dong & Simon, 2013); nursing home placement (Lachs, Williams, O'Brien, & Pillemer, 2002); elder abuse (Dong, Simon, & Evans, 2013), and risk for homelessness (Snowdon, 2011).

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Self-neglect was associated with reduced physical function, depression, executive dysfunction, and drug and alcohol abuse (Dong, Simon, Beck, & Evans, 2010; Dong, Simon, Fulmer, et al., 2010; Dyer, Pickens, & Burnett, 2007; Gibbons, 2009; Pickens et al., 2013).

Ageing populations and medical advances will result in more people living longer in the community with complex co-morbidities. Living alone, isolation, poor social networks, helplessness, and economic decline all have the potential to impact on self-care and create vulnerabilities in relation to SN, self-protection, and safe independent living in the community (Burnett et al., 2006; Lee & Kim, 2014; Spensley, 2008; World Health Organisation United States (US) National Institute of Aging, 2011). Research suggests a pattern between social isolation (Spensley, 2008); lack of access to health services (Choi, Kim, & Asseff, 2009); poor coping (Gibbons, 2009); medical neglect (Burnett et al., 2014); non-compliance with medication (Turner, Hochschild, Burnett, Zulfiqar, & Dyer, 2012); risk for harm (Tierney et al., 2004); homelessness (Snowdon, 2011) and SN. Not all self-neglecting adults demonstrate definite risk factors. Cultural issues and a person's life history can influence intention to SN (Band-Winterstein, Doron, & Naim, 2012; Day, Leahy-Warren, & McCarthy, 2013). All of the above present complex triggers and vulnerabilities which may lead to SN and an array of interrelated social, community, and professional issues. SN cases can present along a continuum of severity and are enormously complex and ethically challenging.

Based on the literature it is clear that SN is a complex multidimensional concept that lacks clarity and is conceptualised in many different ways by researchers, professionals, and communities (Bohl, 2010; Day, McCarthy, & Leahy-Warren, 2012; Gunstone, 2003; Lauder, Scott, & Whyte, 2001; May-Chahal & Antrobus, 2012; McDermott, 2010). Mental health and community nurses have a key role in the identification of self-neglecting adults. Safety and support of vulnerable adults at risk for SN can present complex ethical challenges (Day, Leahy-Warren & McCarthy, 2016). Safeguarding and protective measures, proportionate to assessed risk must be initiated by professionals. However there is a dearth of SN instruments which has led to subjectivity in measurement of SN (Day et al., 2012; Dyer et al., 2006). Previously three instruments have been used to measure SN: Self-Neglect Severity Scale (SSS) (Kelly, Dyer, Pavlik, Doody, & Jogerst, 2008) and two squalor instruments: Living Conditions Rating Scale (LCRS) (Samios, 1996) and the Environmental Cleanliness and Clutter Scale (ECCS) (Halliday & Snowdon, 2009; Snowdon, Halliday, & Hunt, 2013).

The 28 item SSS was developed by the Consortium for Research in Elder Self Neglect (CREST) at Baylor College of Medicine (Kelly et al., 2008). The format encompasses pictorial and risk evaluation to assess three domains: hygiene, functioning, and environment (Dyer et al., 2006; Kelly et al., 2008). Field testing of SSS with 23 community dwelling adults has discriminated between older adults reported as self-neglecting and adults with no history of SN. Statistical evidence has shown that sensitivity and specificity of the SSS were not within standard range of acceptability and the unidimensionality of the scale was unclear (Kelly et al., 2008). No further research on use of this scale has been reported.

Two other scales have relevance as they measure environmental dimensions of SN and squalor. The Living Conditions Rating Scale (LCRS) (20 items) was first presented in an unpublished master's thesis (Samios, 1996). Subsequently the LCRS was used in five studies to measure and assess the home living environments of 83 older adults (Samios, 1996), 87 younger and older adults (Snowdon, 1987), 81 adults living in local authority housing (Halliday & Snowdon, 2009), 173 adults living in squalor (Snowdon & Halliday, 2011), and 108 self-neglecting adults (Leibbrandt, 2007) living in low income housing. Leibbrandt (2007) reported a Cronbach α reliability of 0.89 but few recommendations were made on utility and reliability of the LCRS.

Halliday and Snowdon (2009) developed the 10 item Environmental Cleanliness and Clutter Scale (ECCS) to measure and observe severity of domestic squalor and hoarding. Homes (n = 55) were rated by specialists (n = 2) in old geriatric psychiatry using both the ECCS and the Living Conditions Rating Scale (LCRS) (Samios, 1996). Cronbach's α for LCRS was 0.89 and Cronbach's α for the ECCS was 0.87. Exploratory factor analysis (EFA) was conducted on ECCS scores collected by the Squalor Project team on younger and older people (n = 186) with mean age of 61.5 years. EFA of the ECCS reported a two factor structure (squalor and accumulation of items) (Snowdon et al., 2013).

In summary the SSS, LCRS, and the ECCS focus on SN severity, squalor, and hoarding. These tools fail to capture the contextual and complex physical–psychosocial and environmental risk factors that co-exist with self-neglecting cases. Community nurses have a critical role in home visiting, and early identification, support, and management of adults at risk for self-neglecting. One of the primary reasons why SN is underreported is the lack of a comprehensive, psychometrically evaluated instrument that can assist identification of SN. An objective SN measurement instrument can guide assessment and interventions in relation to SN (Day, 2014).

The literature synthesis was underpinned by the Elder Self-Neglect (ESN) conceptual framework that includes two key dimensions and seven sub-categories: physical/psycho-social (physical health risks, mental health, personal endangerment, and social networks) and environmental (physical living conditions, personal living conditions and financial issues) (Iris et al., 2010). The current study draws on the original work of Iris et al. (2010) in its underpinnings; it also draws on qualitative research (Day et al., 2012, 2013) and an extensive literature review for the development of items. The instrument measure is supported by the ESN conceptual framework that challenges characterisation of SN as a medical syndrome (Day, 2014; Iris et al., 2010). The purpose of this research was to develop and evaluate the psychometric properties of an instrument to measure professional perceptions of self-neglect. Ethical approval was obtained from the Clinical Research Ethics Committee of the University Teaching Hospitals.

DESIGN AND METHODS

A quantitative, descriptive cross-sectional design was used in this two-stage study. Stage 1 involved the item generation, face and content validity, and review and field testing of instrument. Stage 2 involved psychometric evaluation of the newly developed instrument. The methods used to validate the SN instrument included: content validity and face validity (stage 1), construct validity, exploratory factor analysis (stage 2), and reliability tests: internal consistency (Cronbach's α) (stage 2).

An extensive item pool was generated from three sources: literature review; items from ESN conceptual framework (Iris, Ridings and Conrad, 2010); previous qualitative research (Day et al., 2012, 2013) and the appraisal of existing instruments (Day, 2014). The 90 items generated were organised under dimensions and categories of the ESN conceptual framework (Iris et al., 2010).

In stage 1, content validity was established by a panel of 8 purposely selected experts who had a variety of professional background (public health nurses (PHNs), social workers (SWs), senior case workers (SCWs), safeguarding and protection, medicine, gerontology, and rehabilitation) and expertise related to clinical practice, research, leadership and management, academic education, and instrument development. The validity of items was estimated using the Content Validity Index (CVI) (Polit & Beck, 2006). Face validity is based on assessment of experts of how clearly items on the scale reflected the concept being measured (Devon et al., 2007; Polit & Beck, 2010).

The decision was made to rule out any items which had not been classified by at least 6 of the 8 experts, I-CVI ≥0.75 based on literature from Polit, Beck, and Owen (2007) and Lynn (1986) who identified that a minimum score of 0.75 for I-CVI is good when there are 8 experts. Corrected CVI for each subscale (S-CVI) ranged from 0.75 to 1.00 and overall CVI was .875 after removing 28 items. The CVI of the 28 items deleted ranged from 0.125 to 0.625; these deleted items were related to