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Measuring self-neglect among older adults: Translation of the Self-Neglect (SN-37)

Master thesis of nursing science

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Self-neglect is a serious health problem where the individuals fail to meet their basic needs for health, safety and well-being, leading to deterioration in physical, mental, or emotional health. Self-neglectors have difficulties with taking care of their selves and they have nutritional frailty, arthritis, incontinence, vision problems, edema and often overweight. As the number of older adults is rapidly growing, while self-neglect as a serious health problem among older adults is increasing within. It is truly necessary for home care nurses who meets self-neglectors to have an instrument to help to recognize these individuals suffering from self-neglect. The purpose of this study was to identify the most reliable, valid and usable instrument to measure suspected self-neglect to be used in the Finnish context, translate it and validate by content.

There is existing eight (8) instruments to evaluate a possible self-neglect were found by literature review conducted using two databases: PubMed/Medline and CINAHL. All the instruments were assessed using the criteria regarding topic, validity and reliability presented by Zwakhalen and colleagues. The most reliable instrument was the Self-neglect 37 (SN-37). This instrument was forward-back translated from the original English language to Finnish according to standard procedures. After translation of the instrument, expert panel of five (5) members was hold in Finland to assess the content and its suitability. The experts were all experienced nurses with home care work experience.

Panelists accepted the important topic of self-neglect. The SN-37 is conducted in Ireland and there were pointed out some items of the instrument that were argued their relevance and translation. These items were related to social behavior of individual, residence, and social welfare.

The SN-37 is versatile, serving both as a tool for measuring SN and for developing practical interventions. In the future, it will be necessary to test the psychometric properties of the translated SN-37 instrument. The SN-37 is a crucial instrument for assessing potential self-neglect and, more broadly, for evaluating potential service needs in healthcare. It can be used in hospital clinics, home care settings, community health centers and research and policy making.

Keywords: self-neglect, older adult, instrument, measurement scale, translation, expert analysis

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1 INTRODUCTION

Self-neglect is the most common form of older adult abuse form in the United States. Other forms of abuse include physical, sexual, psychological, and financial abuse, as well as neglect by caregivers (World Health Organization 2022). When older adults neglect themselves, they jeopardize their health and safety. An older adult who neglects themselves is unable to take care of their physical or psychological well-being in their daily life. They are unable to maintain hygiene, eat properly, manage their living situation, or take their medications. Self-neglect also involves hoarding possessions. Self-neglect is not a lifestyle choice but a genuine health problem (Teaster et al. 2007, National Center of Elder Abuse 2018). This health problem has been recognized globally (Day & McCarthy 2016).

Self-neglect affects various aspects of an individual's life. Individuals who engage in self-neglect experience impaired functional and psychological capabilities (Dong et al. 2009, Dong & Simon 2016, Dong et al. 2010). Mental illnesses are more commonly diagnosed in self-neglecting older adults compared to those who do not neglect themselves (Frazini & Dyer 2008, Payne & Gainey 2005). Self-neglectors are often suffering from malnutrition (Ernst & Smith 2011, Aung et al. 2006). Older adults who neglect themselves are generally socially isolated from their families, friends, and neighbors, and they often have close relationships with animals (Day et al. 2013). Self-neglecting older adults are at a higher risk of misusing medications (Turner et al. 2012).

By 2050, the number of older adults will double compared to the year 2000 (WHO 2018). Aging will be the biggest transformation of the 21st century and will have an impact on the entire healthcare sector (United Nations 2018). Self-neglect has been found to increase healthcare costs in American studies: older adults who neglect themselves are at a higher risk of hospitalization. The more severe the self-neglect, the greater the risk of hospitalization (Dong et al. 2012). Older adults with self-neglect are more likely to visit the emergency department (Dong et al. 2011) and have longer hospital stays (Dong & Simon 2014). It is important that home care nurses that meet older adults in their work in Finland are familiar with the importance of self-neglect and have a proper measurement scale to evaluate the severity and existence of self-neglect of an older adult. It is not only seen for measuring the possible self-neglect but also to develop interventions in practice (Day et al. 2013). It can be used not only in home care settings, but also in hospital clinics, community health centers, research and in policy making.

In this research the purpose is to identify the most reliable, valid and usable instrument for the measurement of self-neglect to be used in the Finnish context, translate it and validate it by content.

2 LITERATURE REVIEW

The objective of this literature review was to identify possible instruments for the measurement of self-neglect and evaluate their validity and reliability. The search for relevant studies was performed by querying the Pubmed/Medline and CINAHL databases. The literature review was conducted in September 2023, and detailed search terms can be found in Appendix 1. The inclusion criteria encompassed measurement scales specifically designed for older adults dealing with self-neglect. On the other hand, exclusion criteria encompassed measurement scales that address all forms of elder abuse. In Appendix 2 is detailed process of included articles.

Self-neglect is often characterized as an older person's inability or unwillingness to provide for their basic needs. Self-neglect can be characterized to be active neglect (intentional) or passive neglect (unintentional). (Day 2010.) Self-neglect involves a range of behaviors, cumulative self-care deficits and environmental neglect. (Adams & Johnson 2002, Iris et al. 2010)

There are a total of eight (8) assessment instruments specifically created for assessing the potential and severity of self-neglect in older adults. Among these, four have been developed in the United States (Dyer et al. 2006, Iris et al. 2014, Abrams et al. 2018, Wang et al. 2021), two in Europe (Day 2010, Zawisza et al. 2021) and two in Eastern cultures (Ilhan et al., 2018, Motamed-Jahromi et al. 2023) specifically Iran and Turkey. The instruments are presented below in chronological order:

1. The Self-Neglect Severity Scale (SSS) (Dyer et al. 2006).
2. The Elder Self-Neglect Assessment (ESNA) (Iris et al. 2014).
3. The SelfNeglect-37 (SN-37) (Day 2010).
4. The Abrams Geriatric Self-Neglect Scale (AGSS) (Abrams et al. 2018).
5. The Istanbul Medical School Elder Self-Neglect Questionnaire (IMSelf-neglect) (et al. 2018).
6. The Point-Based Predictive Index of Two-Year Incident Self-Neglect (Wang et al. 2021).
7. Self-reported self-neglect scale (SRSNS) and Objective assessment of the level of self-neglect-physical appearance (OALSN-PA) (Zawisza et al. 2021).

8. The Elder Self-Neglect Scale (ESNS) (Motamed-Jahromi et al. 2023).

None of these instruments are currently available in the Finnish language, nor are they utilized in nursing care or healthcare within Finland. The items include observational measurements. After starting the process of this study, there were published a systematic literature review of existing self-neglect instruments (Qion et al. 2021).

Table 1. Instruments for evaluating self-neglect

Name of the instrument	Year of development	Country where developed	Number of items	Type of evaluation	Scale options	Translations into other language
Self-Neglect Severity Scale (SSS) (Dyer et al., 2006)	2006	USA	17	Observation Question	severity rating scale 0 (normal)- 4 (severe self-neglect)	-
The elder self-neglect assessment (ESNA) (Iris et al., 2014)	2014	USA	62	Observation	Yes(problem exists)/ No (problem doesn't exist) / Suspected problem / Don't know / Not applicable	Chinese (C-ESNA) (Wang H 2018)
SelfNeglect-37 (SN-37) (Day 2010)	2016	Ireland	37	Observation Question	Yes / Don't know / No Max 37 point	-

Name of the instrument	Year of development	Country where developed	Number of items	Type of evaluation	Scale options	Translations into other language
The Abrams Geriatric Self-Neglect Scale (AGSS) (Abrams et al., 2018)	2018	USA	6	Question to observer and to subject	Multiple answer 0(no self-neglect)-4(highest level of self-neglect) Max 24point	-
IMFSelf-neglect (Ilhan et al. 2018)	2018	Turkey	11	Questionnaire	Yes / No 1 point to yes answer, max points are 11	-
The Point-Based Predictive Index of Two-Year Incident Self-Neglect (Wang et al., 2021)	2021	USA	19	Question	The information not provided	-

Name of the instrument	Year of development	Country where developed	Number of items	Type of evaluation	Scale options	Translations into other language
Self-reported self-neglect scale (SRSNN) and OALSN-PA (Zawisza et al. 2021)	2021	Poland	6 + 17	Question (self-report) and observation	Each item has its own scale for points. The higher the point, the more possible is self-neglect.	-
ESNS (Motamed-Jahromi et al., 2023)	2023	Iran	26	Question (self-report)	1 (never) / 2 (rarely) / 3 (sometimes) / 4 (often) / 5 (always) Higher points indicate higher possibility for self-neglect	-

The Self-Neglect Severity Scale (SSS) (Dyer et al. 2008) has been developed in the United States in 2006, consists of three domains: A) personal hygiene (5 questions), B) cognitive assessment, health, and safety issues (6 questions), C) environmental assessment (12 questions). Personal hygiene consists of items of hairs cleanliness, skin, odors, infestations and clothing. Cognitive domain consists of questions about shopping, cleaning clothes, handling finances, accessing healthcare, obtaining meals and using telephone. The domain of environment consists items of the apartments bath, kitchen, main living areas, pets and presence of urine or feces. (Dyer et al. 2008)

A professional (proxy) evaluates the points indicated in each domain on a scale of 0 (no self-neglect) to 4 (severe self-neglect). The instrument is targeted to be used in home environment and it takes about five to ten minutes to fill. Almost all the items can be filled through professionals observation (Dyer et al. 2008).

The Elder Self-neglect Assessment (ESNA) (Iris et al. 2014) has been developed in United States in 2014. It has a longer version with 77 items and shorter with 25 items. Items are evaluated by health care professionals. The instrument consists of seven conceptual areas: personal endangerment, environmental, financial issues, mental health, personal living conditions, physical health and social network and culture. Unfortunately, the instrument is not available in the development article (Iris et al. 2014).

The Self-Neglect-37 (SN-37) (Day 2010) was developed in Ireland in 2016. It consists of 37 statements sorted into five different sub-domains. These are the environment (12 statements), social relations (7 statements), feelings and behavior (8 statements), avoiding health care (6 statements) and self-determination (4 statements). The instrument is used by professional observation. You get a point for a positive statement. The maximum score is 37. The higher the score, the more severe the individual's neglect of self-care. (Day 2010.)

The Abrams Geriatric Self-Neglect Scale (AGSS) (Abrams et al. 2018) is an instrument developed in the United States in 2017. It consists of six questions that are answered on a 5-point Likert scale. The questions concern taking medication, self-care, nutrition, environment/housing, managing one's own finances and social interactions. The points for all these subject areas are added together. The maximum score is 24. The higher the score, the more severe the individual's neglect of self-care. (Abrams et al. 2018.) The AGSS is also implemented / adapted for Chinese population with few cultural changes in questions (Yu et al. 2022).

The IMSelf-Neglect questionnaire (Ilhan et al. 2020) is a screening tool for self-neglect which is developed in Turkish language in Istanbul medical school. It consists of questionnaire with 11 items. Questions are for personal hygiene, health habits and social functioning. “Yes” answers get one point each, when the maximum points are 11. The lower the test score, the higher the possibility for self-neglect. (Ilhan et al. 2020.)

A point-based predictive index (Wang et al. 2021) has been developed for Chinese population to evaluate individual’s risk of self-neglect. An individual himself answers the questionnaire and gets points. It has totally 19 items to answer. There is a risk score interpretation: probability of self-neglect compared to individual’s points (Wang et al. 2021.)

Self-Reported Self-Neglect Scale (SRSNS) (Zawisza et al 2021, *Objective Assessment of the Level of Self-Neglect-Physical Appearance (OALSN-PA)* (Zawisza et al 2021) and the *Objective Assessment of the Level of Self-Neglect Standards of Living Arrangements (OALSN-SLA)* (Zawisza et al 2021) are developed in Poland in 2017. They are three scales relatively short to use in daily nursing practice. SRSNS is meant to be used by the individual itself and the other two OALSN-PA and OALSN-SLA are used by health care provider. (Zawisza et al 2021.)

The Elder Self-Neglect Scale (ESNS) (Motamed-Jahromi et. al 2023) has been developed in Iran. It has 36 items that the individual must self-report. The items consist of all the dimensions of self-neglect: environment, social relations, feelings and avoiding health-treatments and self-determination. (Motamed-Jahromi et al. 2023.)

3 AIM AND RESEARCH QUESTIONS

The purpose of this study was to identify the most reliable, valid and usable instrument for the measurement of self-neglect to be used in Finnish context, translate it and validate by content. The goal of this study is to provide an instrument for identifying self-neglect in the older people thus improve the health and well-being of the elderly, and to help detect and address the problem as early as possible.

In this study, the research questions were as follows:

1. What instrument for measuring self-neglect is the most reliable, valid and usable?
2. What is the usability of the most reliable and valid instrument translated to Finnish language?

4 METHODS

4.1 Comparison of instruments

Zwakhaleh et al. (2006) have developed criteria for examining the reliability of Instruments. The criteria include ten evaluated items. Each item is evaluated and scored on a scale of 0-2. The levels of scoring items have been described for the evaluation of each item. The higher the score the instrument gets, the more reliable the instrument is. The maximum score according to the criteria is 20.

The subject of review were 1) origin of topics, 2) number of participants, 3) content validity, 4) criterion validity 5) construct validity compared to other instruments 6) construct validity of the instrument 7) homogeneity, 8) inter-rater reliability, 9) intra-rater reliability and 10) usability. (Zwakhaleh et al. 2006).

Table 2. Scoring by Zwakhaleh et al. 2006 criteria

Origin of topics	Are the items been developed especially for the elderly to measure self-neglect? The instrument gets two points when the items have been developed specifically for people suffering from self-neglect, and one point if the topics have been adapted from another instrument for this target group. Points are not awarded if the measure was developed for a different target group.
Number of participants	The instrument gets two points when there are more than 100 participants in the developing process. One point if there are 50-100 participants and no points if there are less than 50 participants.
Content validity	Two points if the instrument covers all important topics according to the evaluators. And if the content is collected using different sources for a specific population. One point if, according to the evaluators, the instrument covers all important areas in the modified meter. The sub-areas were adopted into the measure and they covered all important areas according to the evaluators. Points are not awarded if, according to the evaluators, the measure does not cover all important areas.
Criterion validity	Two points are given when the correlations are at or above an acceptable level ($r > .60$) according to the "gold standard" or "silver standard". The sensitivity/specificity of the meter has been defined acceptably. One point is given when the correlations are from an average level to an acceptable level ($.40 < r < .60$), according to the "gold standard" or "silver standard". No points are given if the correlations are below $.40$ or this information is not given at all.
Construct validity to other instruments	The instrument gets two points if it correlates above an acceptable level ($r > .60$). One point is given if the correlations are at an average level ($.40 < r < .60$). You don't get a single point. If the correlations are low ($r < .40$).
Construct validity of the instrument	Construct validity in detail, i.e. whether there is self-neglect or not. The instrument gets two points if, according to the evaluators, the measure separates well the elderly who self-neglect from the elderly who do not. The instrument gets one

	point if, according to the evaluators, the meter separates these in an average way. No points if the instrument doesn't specify these or information about this is not given.
Homogeneity	The instrument gets two points if Cronbach's α is between .70 and .90. The instrument gets one point if α is over .90 or between .60-.70. No points are given if α is less than .60 or no information about this is given.
Inter-rater reliability	Two points, if reliability coefficient $> .80$. The instrument gets one point if the reliability coefficient is between .60 and .80. No points if the coefficient is less than .60 or no information is given or if it is based on an interview.
Intra-rater reliability	Two points if the reliability coefficient is over .80. One point is given if the reliability coefficient is between .60 and .80. The instrument will not get any points if the reliability is based on an interview or if the correlation coefficient is less than .60 or no information is given at all.
Usability	The instrument gets two points when the instrument is short, manageable according to the instructions and the interpretation of the scoring is clear. The instrument gets one point when it is manageable no points when the instrument is more complicated.

This study compares eight existing instruments (SSS, ESNA, SN-37, AGSS, IMSelf-Neglect, Point-based predictive index of two-year incident self-neglect, ESNS, SRSNS + OALANS-PA) according to Zwakhalen and colleagues (2006) criteria.

4.2 Translation of the instrument

The most reliable instrument evaluated according to the criteria by Zwakhalen and colleagues (2006) is translated from the original English to Finnish using the double translation method (forward and back-translation) (Maneesriwongul & Dixon 2004). The research received a permission via email from Mary Rose Day, the creator of the instrument, for its translation on February 12, 2019. Professionals from the Language Office and bilingual researchers were used in the translation work. The original selected instrument was translated into Finnish and after the consensus decision of the research team members was translated back into English. After that, the original English instrument is compared with the translated English version. The research team discusses the result and, if necessary, consulted the language agency and the developer of the instrument. (Brislin 1970, Tuleja et al. 2011.)

In this research the focus was on translation process: consistency of concepts, semantic i.e. linguistic consistency, and consistency of criteria (the nature of the subject being examined). The latter means that the standard behind the meter must be the same as the original one. The

format of use of the converted meter must also be the same as the original. (Hilton & Skrutkowski 2002.) However, all the contexts might not be able to translate straight from the original instrument to Finnish language and are more likely to depend on the culture and for example the government programs, health care system of target language's culture (Hilton & Skrutkowski 2002).

The double translation (forward-back translation) method serves as an additional measure of the translation's quality. It also allows for the verification of semantic equivalence between the source of language (SL) English version and the target language (TL) Finnish version. It is time-consuming process, especially when there are constraints of both the time and budget, requiring the involvement of two separate translators. (Maneesriwongul & Dixon 2004.)

4.3 Inter-rater evaluation of content

The translated version of the SN-37 to Finnish was pilot tested the translation by the Finnish native speakers. The purpose was to evaluate content evaluation of the translated instrument of the SN-37: the instructions of the instrument, response format and the clarity of items. The target of this was to evaluate conceptual clarity by preferably six to ten experts. (Yusof 2019, Polit et al. 2007) Experts in this panel required to have knowledge and experience in the field of self-neglect and the target population (=self-neglectors), thus the mother language must have been Finnish. (Sousa et al. 2011.)

In Finland home care nurses are the most typical to meet and evaluate individual's potential self-neglect. In Finland in year 2021 in home care is 74% of nursing staff are practical nurses and 12% are registered nurses or public health nurses (Finnish institute for health and welfare 2023). These may be those professionals using this instrument. It has been suggested that the minimum number of experts can vary based on the purpose but six (6) members in the expert panel is usually agreed. (Yusof 2019, Polit et al. 2007) The experts who are evaluating the translation must suggest to the unclear item some better translation or understanding. The minimum inter-rater agreement among experts is 80% of each translated item. The participating experts are evaluating each translated Finnish item for content equivalence 1= not relevant, 2= unable to assess relevance, 3= relevant but needs minor alteration, 4= very relevant and succinct. (Sousa ym. 2011.)

The results were analyzed by content validity index (CVI) and kappa coefficient (Wynd et al. 2003). All items underwent item relevance assessment using the Item Content Validity Index

(I-CVI), indicating the level of agreement among panelists regarding the relevance and clarity of each item of the instrument. Responses were recorded on a scale from 1 to 4. For the computation of I-CVI, responses were coded, with a score of 1 assigned to responses 3 and 4, and a score of 0 assigned to responses 1 and 2. Subsequently, all coded responses were aggregated and divided by the number of experts. A resulting score of 1 denotes the highest relevance, signifying unanimous agreement among panelists regarding the items' relevance or translation. (Polit et al. 2007.) (Appendix3.)

In this expert panel all the experts were selected from the home care field. They required to have experience in home care and their profession required to be practical nurse or registered nurse. The researcher will hold a brief session to all attendants to clarify the understanding of what self-neglect is among older adults and research. All the experts received a form to review the Finnish translation of the SN-37 (Appendix1). (Sousa et al. 2011.) If certain items reveal a lack of understanding or meaning, a review process will be initiated to provide improved explanations for those items (Blomberg et al. 2019).

Prior to the panel, the author ensured that all participants were well-informed about the research through a comprehensive written information letter (Appendix 4). Furthermore, each participant willingly provided their informed consent (Appendix 5).

The session commenced with the researcher delivering a concise 15-minute presentation, delving into the research, the significance of self-neglect as a health issue, and other relevant aspects. Subsequently, all participants were equipped with evaluation forms to assess the relevance and translation of each item discussed.

5 RESULTS

5.1 The selection of the instrument

Zwakhaleh and colleagues (2006) criteria were employed to scrutinize all the instruments, revealing that the SN-37 emerged as the most psychometrically sound and reliable. None of the instruments demonstrated construct validity when compared to other self-neglect measures, and intra-rater reliability was lacking across the board. With the exception of the SRSNS + OALAN-PA, all instruments received a maximum of two points in the origin of items. The table below provides a comprehensive overview of the ratings assigned to each evaluated instrument.

Table 3 Self-neglect instruments evaluated by Zwakhaleh et al. (2006) criteria

	Origin of the item	Number of participants	Content validity	Criterion validity	Construct validity in relation to other	Construct validity differentiation	Homogeneity	Inter-rater reliability	Intra-rater reliability	Feasibility	TOTAL
SSS	2	0	0	0	0	0	0	0	0	0	2
ESNA	2	2	2	0	0	0	2	0	0	2	10
SN-37	2	2	2	2	0	2	2	2	0	2	16
AGSS	2	1	2	0	0	0	1	1	0	1	8
IMSelf-Neglect	2	0	0	2	0	0	2	2	0	0	8
The Point-Based Predictive Index of Two-Year Incident Self-Neglect	2	2	2	0	0	0	2	0	0	0	8
SRSNS + OALAN-PA	0	2	2	0	0	0	2	0	0	1	7
ESNS	2	2	2	2	0	2	2	0	0	0	12

The SN-37 is an instrument developed in Ireland. The instrument was developed in two stages. In the first stage an item pool of 90 items was created. In stage two the instrument was sent to 566 health and social care professionals across Ireland with 60% or response. The final instrument includes five subscales: i) environment (items 1-12), ii) social networks (items 13-

19), iii) emotional and behavioral liability (items 20-27), iiiii) health avoidance (items 28-33) and v) self-determinism (items 34-37) (Day et al. 2013. Day & McCarthy 2016.)

5.2 Translation

The double translation method was employed to translate the SN-37, a self-neglect instrument, which is considered highly reliable based on Zwakhalen and colleagues' (2016) criteria. Initially, the instrument was translated from English to target language Finnish. Translator was certified translator with experience in health care subject. (see Sousa et al. 2011.) Subsequently, the translated version was rendered back into English from Finnish. A meticulous comparison of the two English versions revealed striking similarities (Sousa et al. 2011). However, it was observed that certain items did not align with the nuances of Scandinavian culture, particularly within the public benefit context (Hilton & Skrutkowski 2002)

Table 4. SN-37 translation from English to Finnish # Original items © Day 2010 – with permission the exclusive and assignable legal right, given to the originator for a fixed number of years, to print, publish, perform, film, or record literary, artistic, or musical material

Original item	Translated into Finnish	Back-translated
Environment	Ympäristö	Environment
Individual has no way to obtain and/or prepare meals	Henkilöllä ei ole mahdollisuuksia hankkia ja/tai valmistaa aterioita	The person does not have the opportunity to purchase and/or prepare meals.
Individual lives in a house/apartment that does not have all the equipment/ facilities to fit the individual's physical needs (i.e. wheelchair, bars in the bathroom or hallway or ramps, poor lighting, fuel poverty).	Henkilö asuu talossa/asunnossa, jossa ei ole kaikkia henkilön fyysisten tarpeiden edellyttämiä varusteita/tiloja (esim. pyörätuoli, kaiteet kylpyhuoneessa tai käytävässä, luiskat, huono valaistus, energiaköyhyys).	The person lives in a house/apartment that is lacking some of the equipment/spaces required to meet the person's physical needs (e.g. a wheelchair, railings in the bathroom or hallway, ramps, poor lighting, energy poverty).
Individual has an accumulation of items that presents a safety hazard.	Henkilölle on kertynyt esineitä, jotka muodostavat turvallisuusriskin.	The person has collected items that pose a safety risk.
Individual lives in a house/apartment that is very cold.	Henkilö asuu hyvin kylmässä talossa/asunnossa	The person lives in a very cold house/apartment.
Individual lives in a house/apartment that is unsafe (i.e. fire hazards, reduced)	Henkilö asuu talossa/asunnossa, joka ei ole turvallinen (esim. tulipalovaara).	The person lives in a house/apartment that is not safe (e.g. there is a fire hazard).
Individual is hoarding animals.	Henkilö kerää eläimiä.	The person collects animals.
Individual is eating spoiled food.	Henkilö syö pilaantunutta ruokaa.	The person eats spoiled food.
Individual has no access to bathing facilities.	Henkilöllä ei ole käytössään peseyymistiloja.	There are no washing facilities available to the person.

Original item	Translated into Finnish	Back-translated
Individual lacks funds/money to pay bills (i.e. utilities, structural, household repairs, etc.)	Henkilöllä ei ole varaa/rahaa laskujen maksamiseen (esim. sähkö- tai vesilasku, asunnon peruskorjaus, kodin pienet korjaustyöt jne.)	The person cannot afford to pay bills (e.g. electricity or water bills, basic home renovation work, minor repairs, etc.).
Individual lives in a house/apartment where there is evidence of vermin.	Henkilö asuu talossa/asunnossa, jossa on merkkejä tuhoeläimistä.	The person lives in a house/apartment that shows signs of pests.
Individual does not pay household bills despite having adequate income to pay them.	Henkilö ei maksa kotitalouteen liittyviä laskuja, vaikka hänen tulonsa riittävät niiden maksamiseen.	The person does not pay household-related bills, even though their income is sufficient to do so.
Individual lives in a house/apartment where appliances are not working (sinks, refrigerator, lighting, phone, etc.).	Henkilö asuu talossa/asunnossa, jonka laitteet eivät toimi (pesualtaat, jääkaappi, valaistus, puhelin jne.)	The person lives in a house/apartment in which appliances or fittings do not work (sinks, refrigerator, lighting, telephone, etc.).
Social networks	Sosiaaliset verkostot	Social networks
Individual is socially disconnected or has limited social relations with neighbours	Henkilö on sosiaalisesti eristäytynyt tai hänen sosiaaliset suhteensa naapureiden kanssa ovat rajalliset	The person is socially withdrawn, or their social relations with their neighbours are limited.
Individual has not talked to someone in past week	Henkilö ei ole puhunut kenenkään kanssa kuluneen viikon aikana.	The person has not spoken to anyone over the last week.
Individual is living alone.	Henkilö elää yksin.	The person lives alone.
Individual lacks social contact (family, friends, neighbours) to turn to in an emergency	Henkilöllä ei ole läheisiä (perhe, ystävät, naapurit), joiden puoleen kääntyä hätätilanteessa.	The person has no loved ones (family, friends, neighbours) to turn to in an emergency.
Individual avoids friends, family, religious or social events.	Henkilö välttelee ystäviä, perhettä, uskonnollisia tai yhteisöllisiä tilaisuuksia.	The person avoids friends and family, religious or communal events.

Original item	Translated into Finnish	Back-translated
Individual's contact with family members, friends and neighbours is less frequent than necessary to attend to his/her needs.	Henkilön yhteydenpito perheenjäsenten, ystävien tai naapurien kanssa on harvempaa kuin hänen tarpeensa edellyttävät.	The person's contact with their family members, friends or neighbours is less than their needs require.
Individual does not have anyone to provide him/her with the assistance he/she needs.	Henkilöllä ei ole ketään, joka tarjoaisi hänelle hänen tarvitsemaansa apua.	The person has no-one to offer them the help they need.
Emotional and Behavioural Labiality	Tunne-elämän ja käyttäytymisen epävakaisuus	Emotional instability and unstable behaviour
Individual displays fear in daily situations.	Henkilö osoittaa pelkoa päivittäisissä tilanteissa.	The person shows fear in day-to-day situations.
Individual expresses fear of certain people who are close to him/her.	Henkilö osoittaa pelkoa tiettyjä läheisiä ihmisiä kohtaan	The person shows fear towards certain loved ones.
Individual demonstrates aggressive, hostile behaviour	Henkilö käyttäytyy aggressiivisesti ja vihamielisesti.	The person behaves aggressively and angrily.
Individual is placing trust In people who have proven not to be trustworthy	Henkilö osoittaa luottamusta sellaisia ihmisiä kohtaan, jotka eivät ole osoittautuneet luottamuksen arvoisiksi.	The person shows trust in people who have proven untrustworthy.
Individual's behaviours are likely to cause physical harm to others.	Henkilön käytöksestä aiheutuu todennäköisesti muille fyysistä haittaa.	The person's behaviour will probably cause physical harm to others.
Individual has not left his/her house/apartment for more than one month.	Henkilö ei ole poistunut talostaan/asunnostaan yli kuukauteen.	The person has not left their house/apartment for more than a month.
Individual appears sad (i.e. unhappy, gloomy, mournful).	Henkilö vaikuttaa surulliselta (esim. onneton, synkkä, surumielinen).	The person seems sad (e.g. unhappy, gloomy, miserable).
Individual is overusing drugs/alcohol.	Henkilö käyttää liikaa huumeita/alkoholia.	The person uses an excessive amount of drugs/alcohol.
Health avoidance	Terveysteen liittyvä välttäminen	Health-related avoidance

Original item	Translated into Finnish	Back-translated
Individual has unattended foot problems	Henkilöllä on hoitamattomia jalkaongelmia	The person has untreated foot problems.
Individual ignores signs and symptoms of disease.	Henkilö jättää sairauden merkkejä tai oireita huomioimatta.	The person ignores signs or symptoms of illness.
Individual lacks follow-through with preventive or diagnostic testing related to health conditions.	Henkilö jättää kesken terveydentilaansa koskevat ennaltaehkäisevät tai diagnostiset tutkimukset.	The person fails to complete preventative or diagnostic tests relating to their state of health.
Individual does not comply with the prescribed medical treatment (under/ over medication, or the consumption of medication that was not prescribed) despite a clear understanding of the rationale for regimen recommendations.	Henkilö ei noudata hänelle määrättyä lääkehoitoa (lääkkeen ali-/liikakäyttö, tai muun kuin määrätyn lääkityksen käyttäminen), vaikka hän ymmärtää hyvin hoito-ohjelman suositusten perustelut.	The person does not comply with the medical treatment prescribed for them (under- or overuse of medicine, or use of medicine other than that which was prescribed), even though they fully understand the reason for the recommended treatment programme.
Individual hoards medication.	Henkilö hamstraa lääkkeitä.	The person hoards medicines.
Individual presents with recent unplanned weight loss	Henkilöllä on havaittavissa hiljattain tapahtunutta tahatonta painonlaskua.	The person shows visible signs of recent, unintentional weight loss.
Self-Determinism	Itsemäärääminen	Autonomy
Individual is not co-operative or willing to accept assistance	Henkilö ei ole yhteistyöhaluinen tai ei halua ottaa apua vastaan.	The person is not willing to cooperate or does not wish to accept help.
Individual has displayed self-neglectful behaviour at other times in his/her life	Henkilö on muissa elämänsä vaiheissa osoittanut itsensä laiminlyöntiin viittaavaa käytöstä.	The person's behaviour has indicated self-neglect at other stages in their life.
Individual is reluctant to receive help for daily care.	Henkilö on haluton ottamaan vastaan apua päivittäisiin toimiin.	The person is unwilling to receive help with day-to-day errands and tasks.
Individual neglects personal hygiene (dirty clothing, bad odour, dishevelled appearance).	Henkilö osoittaa piittaamattomuutta henkilökohtaista hygieniaa kohtaan (likaiset vaatteet, paha haju, huolittelematon olemus).	The person shows indifference towards personal hygiene (dirty clothes, bad odour, unkempt appearance).

5.3 Inter-rater evaluation of translation

The expert panel distinguished on the 8th February 2024, from 13:00 to 15:00. From seven invited experts, five were attending the panel. Among the panelists three were registered nurses and two practical nurses, both an average of 13 years of practical experience each.

The panelists unanimously acknowledged the health issue of self-neglect, and they even shared specific instances of clients grappling with self-neglect. Additionally, all panelists concurred on the issue's significance and the prevailing lack of knowledge in the field.

5.3.1 Inter-rater reliability of items

In general, the panelists were agreeing the items in terms of relevance and their clarity of translation into Finnish. Only one item (item14) got lower I-CVI result. (Table4).

Kappa Coefficient is the most commonly used to statistics to test reliability and it is indicating the interrater reliability of items. Kappa can range from -1 to 1. Kappa statistic above 0.41 is acceptable for the item in health-related studies. (McHugh 2012.) There were two items (item15 and item 18) that were below this. Most of the items had a Kappa value 0 which means that all the experts answered the same.

Table 5. Expert panel statistics

Item	I-CVI	Kappa Coefficient	Comments
Henkilöllä ei ole mahdollisuuksia hankkia ja/tai valmistaa aterioita	Relevance item 1 Translation item 1	0,55	"Ei välttämättä toteudu kaikkien kohdalla"
Henkilö asuu talossa/asunnossa, jossa ei ole kaikkia henkilön fyysisten tarpeiden edellyttämiä varusteita/tiloja (esim. pyörätuoli, kaiteet kylpyhuoneessa tai käytävässä, luiskat, huono valaistus, energiaköyhyys).	Relevance item 1 Translation item 1	0	"Väittämä laaja, voisiko apuvälineet vielä erillistää?"
Henkilölle on kertynyt esineitä, jotka muodostavat turvallisuusrisikin.	Relevance item 1 Translation item 1	0	
Henkilö asuu hyvin kylmässä talossa/asunnossa	Relevance item 1 Translation item 1	0	
Henkilö asuu talossa/asunnossa, joka ei ole turvallinen (esim. tulipalovaara).	Relevance item 1 Translation item 1	0	
Henkilö kerää eläimiä.	Relevance item 1 Translation item 1	0	
Henkilö syö pilaantunutta ruokaa.	Relevance item 1 Translation item 1	0	

Item	I-CVI	Kappa Coefficient	Comments
Henkilöllä ei ole käytössään peseytymistiloja.	Relevance item 1 Transalation item 1	0	
Henkilöllä ei ole varaa/rahaa laskujen maksamiseen (esim. sähkö- tai vesilasku, asunnon peruskorjaus, kodin pienet korjaustyöt jne.)	Relevance item 1 Transalation item 1	0	
Henkilö asuu talossa/asunnossa, jossa on merkkejä tuhoeläimistä.	Relevance item 1 Transalation item 1	0	
Henkilö ei maksa kotitalouteen liittyviä laskuja, vaikka hänen tulonsa riittävät niiden maksamiseen.	Relevance item 1 Transalation item 1	0	
Henkilö asuu talossa/asunnossa, jonka laitteet eivät toimi (pesualtaat, jääkaappi, valaistus, puhelin jne.)	Relevance item 1 Transalation item 1	0	
Sosiaaliset verkostot			
Henkilö on sosiaalisesti eristäytynyt tai hänen sosiaaliset suhteensa naapureiden kanssa ovat rajalliset	Relevance item 1 Transalation item 1	0,55	"Epäsosiaalinen ihminen voi tästä huolimatta olla kykenevä itsestään huolehtimiseen" "Sosiaalinen erakoituminen olennainen, mutta suhteet naapureihin vaatii lisää mietintään"
Henkilö ei ole puhunut kenenkään kanssa kuluneen viikon aikana.	Relevance item 1 Transalation item 1	0	
Henkilö elää yksin.	Relevance item 0,4 Transalation item 0,8	0,21	"Ei välttämättä tavoita siitä SN" "Yksin asuvalla silti voi olla useita keinoja itsestään huolehtimiseen" "Oleellista, kun muutkin tekijät otetaan huomioon"
Henkilöllä ei ole läheisiä (perhe, ystävät, naapurit), joiden puoleen kääntyä hätätilanteessa.	Relevance item 1 Transalation item 1	0	"Ei välttämättä itse aiheutettua -> voi kylläkin johtaa muihin tekijöihin."
Henkilö välittelee ystäviä, perhettä, uskonnollisia tai yhteisöllisiä tilaisuuksia.	Relevance item 1 Transalation item 1	0	
Henkilön yhteydenpito perheenjäsenten, ystävien tai naapurien kanssa on harvempaa kuin hänen tarpeensa edellyttävät.	Relevance item 0,8 Transalation item 0,8	0,38	"Riippuu" "Vaikea määrittää yksilön tarve"
Henkilöllä ei ole ketään, joka tarjoaisi hänelle hänen tarvitsemaansa apua.	Relevance item 0,8 Transalation item 1	0,58	"Onko kontaktia ulkopuoliseen apuun tai tieto/halu mistä saada apua"
Tunne-elämän ja käyttäytymisen epävakaisuus			
Henkilö osoittaa pelkoa päivittäisissä tilanteissa.	Relevance item 1 Transalation item 1	0	

Item	I-CVI	Kappa Coefficient	Comments
1. Henkilö osoittaa pelkoa tiettyjä läheisiä ihmisiä kohtaan	Relevance item 1 Transalation item 1	0	
2. Henkilö käyttäytyy aggressiivisesti ja vihamielisesti.	Relevance item 1 Transalation item 1	0	
3. Henkilö osoittaa luottamusta sellaisia ihmisiä kohtaan, jotka eivät ole osoittautuneet luottamuksen arvoisiksi.	Relevance item 1 Transalation item 1	0	
4. Henkilön käytöksestä aiheutuu todennäköisesti muille fyysistä haittaa.	Relevance item 0,8 Transalation item 0,8	0	"Millainen käytös?"
5. Henkilö ei ole poistunut talostaan/asunnostaan yli kuukauteen.	Relevance item 0,8 Transalation item 0,8	0	"Riippuu" "Siitä huolimatta jotkut kykenevät huolehtimaan itsestään"
6. Henkilö vaikuttaa surulliselta (esim. onneton, synkkä, surumielinen).	Relevance item 1 Transalation item 1	0	"Hyvin tapauskohtainen"
7. Henkilö käyttää liikaa huumeita/alkoholia.	Relevance item 1 Transalation item 1	0	
Terveyteen liittyvä välttäminen			
8. Henkilöllä on hoitamattomia jalkaongelmia	Relevance item 1 Transalation item 1	0	"?"
9. Henkilö jättää sairauden merkkejä tai oireita huomioimatta.	Relevance item 1 Transalation item 1	0	
10. Henkilö jättää kesken terveydentilaansa koskevat ennaltaehkäisevät tai diagnostiset tutkimukset.	Relevance item 1 Transalation item 0,8	0	"Tässä voisi olla esimerkkejä testeistä, jotta väittämän ymmärtäisi paremmin"
11. Henkilö ei noudata hänelle määrättyä lääkettä (lääkkeen ali-/liikakäyttö, tai muun kuin määrätyn lääkityksen käyttäminen), vaikka hän ymmärtää hyvin hoito-ohjelman suositusten perustelut.	Relevance item 1 Transalation item 1	0	
12. Henkilö hamstraa lääkkeitä.	Relevance item 1 Transalation item 1	0	
13. Henkilöllä on havaittavissa hiljattain tapahtunutta tahatonta painonlaskua.	Relevance item 1 Transalation item 1	0	
Itsemäärääminen			
14. Henkilö ei ole yhteistyöhaluinen tai ei halua ottaa apua vastaan.	Relevance item 1 Transalation item 1	0	
15. Henkilö on muissa elämänsä vaiheissa osoittanut itsensä laiminlyöntiin viittaavaa käytöstä.	Relevance item 1 Transalation item 1	0	
16. Henkilö on haluton ottamaan vastaan apua päivittäisiin toimiin.	Relevance item 1 Transalation item 1	0	
17. Henkilö osoittaa piittaamattomuutta henkilökohtaista hygieniaa kohtaan (likaiset vaatteet, paha haju, huolittelematon olemus).	Relevance item 1 Transalation item 1	0	

Next, the experts' assessments and discussion regarding the items on the five sub-scales will be presented.

5.3.2 Environment sub-scale

In the first sub-scale, focused on "environment," the panelists generally agreed on the relevance and translation of the items. However, a disagreement arose regarding the first item (item 1) "Individual has no way to obtain and/or prepare meals", questioning whether it is feasible to measure an individual's self-neglect when they lack the facilities for preparing food. Some argued that having physical limitations for food preparation should not categorize an individual as a self-neglector. Another point of contention was the length of the second item (item 2) "Individual lives in a house/apartment that does not have all the equipment/ facilities to fit the individual's physical needs (i.e. wheelchair, bars in the bathroom or hallway or ramps, poor lighting, fuel poverty)"; practical suggestions were made to separate the aids from the item. Furthermore, it was noted that the lack of fuel in the house may not align with the Finnish infrastructure for heating houses.

During the discussion of item nine (9) "Individual does not pay household bills despite having adequate income to pay them", an argument emerged, contending that the item might not align with Finnish culture. The rationale behind this viewpoint was that, since the state provides individuals with income and covers basic utility bills, the concept expressed in the item may not be applicable. However, it was acknowledged that self-neglect could still manifest if an individual refrains from applying for state income support due to financial constraints.

Item 12 "Individual lives in a house/apartment where appliances are not working (sinks, refrigerator, lighting, phone, etc.)." was also deliberated upon, and there was a suggestion to integrate it with item two (2). The discussion revolved around the observation that these two items encompassed the same theme.

5.3.3 Social network sub-scale

The second sub-scale, which centered on "social network" and comprised seven (7) items, proved to be the most contentious during the panel discussion. Overall, the panelists engaged in a robust debate highlighting the distinctions in social culture between Ireland and Finland.

The primary point of contention arose with the first item 13 "Individual is socially disconnected or has limited social relations with neighbors", which categorizes an individual as at risk for

self-neglect if they have limited connections with neighbors. Panelists argued that in Finland, it is commonplace for individuals not to have close or any relationships with neighbors, a perspective that contrasts with the implication of the item. Moreover, in the discussion surrounding item 13, the panelists contended that an individual might already experience social disconnection due to emerging health problems, such as impaired memory, vision, or hearing. It was emphasized that experiencing such health issues should not automatically label the individual as a self-neglector.

The ensuing item 14 “Individual has not talked to someone in past week”, sparked a substantial debate among the panelists regarding whether it is deemed a problem or abnormal in Finland if an individual refrains from speaking to anyone throughout the week. Consensus emerged among the panelists that Finland has a substantial population of introverts who may choose not to engage in conversations without being classified as self-neglectors. It was posited during the discussion that this item should take into account a comparative analysis of the individual's previous behavior: "Was the individual previously socially active, and does the current lack of connection and avoidance of conversation differ from their past behavior?" The discourse also delved into the consideration of whether loneliness is genuinely problematic for the individual.

Item 15 “Individual is living alone”, faced criticism for its perceived lack of relevance in the context of Finland. The critique stemmed from the observation that Finland possesses a highly individual-oriented culture, with approximately half of the households in the country designed for a single occupant. As such, panelists questioned the applicability of this item in a cultural setting where living alone is a prevalent and socially accepted norm. Similarly, as observed with the preceding item, the panelists collectively acknowledged that the assessment of item 15 should be contingent upon a thoughtful consideration and comparison with the individual's history and preferences. Questions were raised, such as whether the individual has consistently lived alone or if their current living circumstances indicate a deviation from their established lifestyle. This reflective approach aimed to discern whether the individual's situation was a matter of personal choice or a result of adverse living conditions. (Official Statistics of Finland 2022.)

Additionally, item 16 “Individual lacks social contact (family, friends, neighbors’) to turn to in an emergency”, underwent discussion among the panelists. It was collectively recognized that this circumstance might not always be a conscious choice of the individual and, therefore, should not be hastily labeled as an indicator of self-neglect.

In a similar vein, item 17 “Individual avoids friends, family, religious or social events.”, was scrutinized by the panelists. They reached a consensus that this item, too, should be evaluated in comparison with the individual's history. If the individual has consistently exhibited a pattern of avoiding such interactions throughout their life, it should not automatically classify them as a self-neglector. The importance of contextualizing these behaviors within the broader scope of the individual's personal history was emphasized during the discussion.

As well as some previous items also the item 18 “Individual's contact with family members, friends and neighbors is less frequent than necessary to attend to his/her needs.” got some arguments from the cultural perspective by panelists. As discussed previously it is more common in Finland and the older generation to survive alone although it is not possible. It is culturally approved not to ask help although needed.

Regarding the final item of the sub-scale, "Individual does not have anyone to provide him/her with the assistance he/she needs," the discussion highlighted a notable absence—the inclusion of the state's social service. The panelists recognized that even if an individual lacks personal connections for assistance, everyone in Finland has an access to the state's social welfare system. Additionally, it was noted that Finnish culture, in comparison to, for example, Irish culture, commonly involves less direct involvement of children in the lives of their parents. This cultural nuance led to the consensus that this particular item may not necessarily indicate self-neglect in the Finnish context, given the prevalent reliance on state services and the cultural norms surrounding familial relationships.

5.3.4 Emotional and behavioral lability sub-scale

The third sub-scale, encompassing the emotional and behavioral lability of the individual, garnered general agreement among the panelists. However, certain items within the sub-scale were noted to lack clarification, according to panelists' opinions.

Concerning the item 20 "Individual displays fear in daily situations," the panelists raised questions about the nature of the fear—whether it pertains to concerns like the fear of medication being poisoned or fear related to daily tasks like preparing food. They suggested that the item needs additional clarification on the concept of fear to be effectively applied by home care nurses in Finland.

Similar discussions unfolded regarding item 21 "Individual expresses fear of certain people who are close to him/her." The panelists sought clarification on the type of fear involved and

whether there were observable changes in the individual's behavior concerning this fear over time.

Item number 24 "individual's behaviors likely to cause physical harm to others," was generally accepted by the panelists, but they felt it required clarification on whether "others" solely referred to humans or also included animals. The panelists discussed whether the behavior of the individual causing harm to animals should be considered in this context.

As for item 25 "Individual has not left his/her house/apartment for more than one month," panelists argued that in Finland, such a situation might be a deliberate choice by the individual, without any negative impact. From a cultural perspective, the panelists expressed that this should not be a definitive indicator of self-neglect, as it could align with an acceptable and deliberate lifestyle choice.

Lastly, item 26 "Individual appears sad (i.e., unhappy, gloomy, mournful)," prompted discussions among the panelists about individuals in Finland who may have a generally sad appearance but not necessarily be facing a problem. The panelists agreed that having a gloomy life attitude is not indicative of self-neglect in Finland, emphasizing the importance of comparing the individual's current appearance to their historical demeanor to assess any significant changes.

5.3.5 Health avoidance sub-scale

The fourth sub-scale focused on items related to health avoidance. Overall, the panelists reached a consensus on the section, acknowledging the relevance of the problems associated with self-neglect.

While the panelists agreed on the relevance and translation of all items in this section, attention was drawn to item 30 "Individual does not comply with the prescribed medical treatment (under/over medication, or the consumption of medication that was not prescribed) despite a clear understanding of the rationale for regiment recommendations." Discussion ensued, suggesting that this item could be made more concise and succinct.

Similarly, item 33 "Individual presents with recent unplanned weight loss," was singled out during the discussions. The panelists recognized it as the only item in the sub-scale that explicitly considers the individual's history and changes in behavior. This item was viewed as

particularly valuable for assessing self-neglect by examining whether the weight loss is a recent and unexpected development in the individual's life.

5.3.6 Self-determinism sub-scale

The final fifth sub-scale delved into individuals' self-determination. The panelists collectively affirmed the relevance and effective translation of the items in this section. However, specific details were raised during the panel discussion, particularly concerning item 34 “Individual is not co-operative or willing to accept assistance” and 36 “Individual is reluctant to receive help for daily care”.

In reference to these items, the panelists pondered whether the helpers mentioned were specifically referring to relatives or professionals home care nurses. The discussion brought to light the nuanced distinction that some individuals might be more receptive to assistance from home care nurses while being resistant to help from relatives.

Moreover, item 35, stating "Individual has displayed self-neglectful behavior at other times in his/her life," was underscored as significant in the discussions. The panelists emphasized the importance of comparing the individual's history, recognizing that this item adds value by considering whether self-neglectful behaviors have manifested at various points in the person's life.

6 DISCUSSION

6.1 Discussion of the results

This study provided a systematic process for identifying and evaluating the most promising instrument for the measurement of self-neglect of older people, translating the instrument into Finnish language and expert analysis of its content, clarity and usability in the Finnish context. The growing number of older people and the policies promoting increased home care underscore the importance of this research and the need for the instrument in home care settings. It is crucial for the usability and recognition of self-neglect that the instrument can be applied effectively in the Finnish context.

There were existing eight (8) instruments to measure self-neglect in older adults. All instruments were evaluated by Zwakhalen and colleagues' criteria (2006). The SN-37 was evaluated as psychometrically the most reliable instrument. The SN-37 was double translated from the original English language to Finnish language. After the translation the expert panel was held with five (5) experts in total to evaluate and discuss the translated Finnish version of SN-37 which is originally developed in Ireland. The context in Europe was considered also similar enough to select this instrument to be translated and validated by content into Finnish context (Cha et al. 2007, WHO 2010).

The SN-37 translation and content validation of translated instrument interrater evaluation was good. Most of the items had a Kappa Coefficient of 0, indicating that all the panelists evaluated the items in exactly the same way. Few items (items 1,13,15,18,19) got more than 0 (0,21-0,55) Cohen's Kappa. These items can be considered as ones where the panelists did not agree on their translation and content validity. Most of the items were assessed in terms of content using I-CVI value of 1, indicating that the panelists agreed on both the relevance and the clarity of the translation. Few items (items 15,18,19,24,25,30) had I-CVI lower than one, mostly because of the cultural differences between original instruments Irish culture and Finnish.

Panelists agreed to importance of topic of self-neglect. In the "environment" sub-scale, panelists largely agreed on the relevance and translation of most items, but notable disagreements emerged. Item 1 sparked debate over the feasibility of measuring self-neglect in individuals without food preparation facilities, with some arguing that physical limitations should not equate to self-neglect. Additionally, the length of the second item was criticized, prompting suggestions to separate aid-related aspects. Concerns were also raised about the relevance of

certain items to Finnish infrastructure and culture, particularly regarding heating fuel and state-provided income and utility support. Item 9 was questioned for its cultural applicability, while item 12 was suggested to be merged with item 2 due to thematic overlap.

The second sub-scale, focusing on the "social network" and comprising seven items, sparked significant debate among the panelists, particularly concerning cultural differences between Ireland and Finland. Item 13, which links limited neighbor connections to self-neglect risk, was contentious as Finnish individuals often do not maintain close neighborly relationships. Panelists also noted that health issues causing social disconnection should not automatically classify someone as a self-neglector. Item 14, concerning weekly social interactions, faced criticism due to the high number of introverts in Finland, suggesting the need to consider an individual's past social behavior. Item 15, addressing solitary living, was debated for its relevance given Finland's prevalent single-occupant households, emphasizing the need to compare current and past living arrangements. Item 16, about lacking emergency contacts, was noted not always to be a matter of personal choice and should not necessarily indicate self-neglect. Item 17, regarding avoidance of social events, also required historical context to avoid misclassification. Item 18, on infrequent contact with family and friends, highlighted cultural norms of Finnish independence, where seeking help is less common despite necessity. Lastly, the final item of the sub-scale on lacking personal assistance overlooked the role of the state's social services, which are accessible to all, indicating cultural differences in familial involvement and reliance on state support in Finland.

The fourth sub-scale addressed items related to health avoidance, with panelists reaching a consensus on the relevance of issues linked to self-neglect. While agreement was found on the translation and pertinence of all items, item 30, concerning non-compliance with prescribed medical treatments, prompted suggestions for a more concise phrasing. Item 33, which mentions recent unplanned weight loss, was noted for its unique emphasis on the individual's history and behavioral changes. This item was deemed especially valuable for assessing self-neglect by identifying recent and unexpected developments.

The fifth sub-scale focused on individuals' self-determination, with panelists affirming the relevance and effective translation of its items. Notable discussions arose around item 34 and 36 which considered how the individual receives help from others. It was noted that some individuals might accept help from nurses but resist assistance from relatives.

The panelists were also deliberating on how this instrument aligns with the acute life situations of older adults, and whether there are any guidelines for its application in such scenarios like death of a close relative.

The translated SN-37 instrument can be used in various contexts in Finland where assessing self-neglect is crucial. Hospital, clinics and geriatric care units can use SN-37 to identify patients at risk of self-neglect and implement the necessary support measures. SN-37 instrument is a tool for home care nurses and social workers not only identify and screen possible self-neglect but also tailor personalized care plans and monitor changes in the individual's ability to care for themselves. It could be a part of the routine health assessment, especially for those individuals who not regularly visit healthcare facilities. Not only in practice, but SN-37 can also be used in research, policy making and healthcare professionals education.

6.2 Validity of the study

Reliability in research is crucial when evaluating the credibility of the research (Gerrish et al. 2010). The researcher involved in this study is a master's student of health sciences, and this investigation marks her inaugural experience in the field of research. This might be evaluated as a lack of reliability in research. The research began in 2018 and concluded in 2024. However, progress stalled for a couple of years during this period, potentially affecting the study's reliability. Initially, the study aimed to pilot test the instrument in home care settings to evaluate its usability in the Finnish context through inter-rater evaluation. This original plan received permission from the city of Turku and ethical approval from the University of Turku's ethical committee. The pilot test was set to commence, but the Covid-19 pandemic halted it, leading to a change in plans to conduct an expert panel instead.

The subject was common for the author as the master thesis was the continuation of the bachelor thesis (Hämäläinen 2017). In this study the literature review was focusing on the existing instruments that measure self-neglect. The review of the literature was conducted, and the instruments were recognized. The author's used search terms were well selected with the supervisor of the study and the validity of the search and existing instruments were valid and followed the standard protocols for evaluation and translation.

Furthermore, the double translation of the instrument was done, and the final translation was reviewed in the research team of the University of Turku. The reliability of the double translation result was enhanced by the involvement of the research team of the University of

Turku. The teams experience and scientific thinking was increasing the validity of the final translation from the double translation.

In the beginning of the study the research plan was to evaluate the translation by two inter rater evaluators in the real field and suspected self-neglectors of home care. The evaluators were planned to be the author and one registered nurse from the home care team of the municipality of Turku. Due the covid pandemic, the original field-testing plan needed to change for expert panel. Expert team was well selected experts in home care field with many years of experience working in home care in Finland. Selecting panelists both registered nurses and practical nurses were enriching the discussion of the theme. Although the professions are working in the same field, the background of education and the tasks of the work in home care differ. This is an increasing issue in the matter of the validity of the expert panel.

6.3 Ethical considerations

This study adhered to research integrity TENK (Tutkimuseettinen neuvottelukunta. (2023)). The entire study, including each step, was conducted with reliability, honesty, respect, and responsibility. Each step and scientific activity in this study are carefully planned, implemented, and documented, adhering as closely as possible to the principles of open science.

The issue concerning self-neglect is sensitive (Lachs et al. 2015). In the beginning, the plan was to pilot test the translated measurement scale in real population and customers in home care. Due the Covid-19 pandemic this original plan was not possible to investigate. After restarting the research again in 2023 the literature review was updated, and the plan of pilot testing changed to expert panel. All the panelists were informed with written information letter of the research and were asked to sign written informed content to attend the panel. In this study the informants were experts. The study ensured that scientific activities do not endanger the health and safety of researchers and research subjects and showed respect for colleagues, participants and society. For background information the panelists were asked to fill the years of experience working in home care and their education. Other information about the panelists were not collected. (Tutkimuseettinen neuvottelukunta 2023.)

Before starting the collection of research material, the study ensured that all necessary permits, consents, and ethical pre-assessments are obtained. The study received permission via email from the creator of the instrument, for its translation on February 12, 2019. Ethical approval was obtained committee from the ethical committee of the University of Turku. All scientific

activities in accordance with the rules and guidelines of your nursing science, following the HTK instructions. Additionally, the study did not have any funding sources and any affiliations for partners and targets involved in the scientific activities. (Tutkimuseettinen neuvottelukunta 2023.)

6.4 Conclusions

The number of older adults is radically growing (Official Statistics Finland 2024). The policies of health care are focusing on home care and possibilities to utilize technical solutions (A strong and committed Finland 2023). In Finnish media there are discussions at intervals that the elderly people cannot contact the health care workers nor get the needed help for health issues or the needs of the individual are not identified by professionals.

Self-neglect is a crucial health problem that should be recognized and easy to identify by health care professionals meeting self-neglectors. An instrument that helps the professionals in the identifying process is necessary for better health and well-being of older people. This study provided an instrument, the SN-37 Finnish version to be used. Although it was translated and validated by content, it was not yet used in the population for assessing and examining its validity and reliability. Based on the original instrument (Day 2010, Day et al. 2016) the usability of the instrument in clinical work as well has been supported.

6.5 Suggestions for further research

In the future, it will be necessary to test the psychometric properties of the translated SN-37 instrument. That may happen in conducting the similar research initiative that was originally planned for the study and that did not happen due to the Covid-19 pandemic. The use of the Finnish version of the SN-37 may prove to be a good tool for use in home care context and in out of hours clinics for evaluation the phenomenon of self-neglect in older people. The sampling may be challenging but the staff and experts in the panel did recognize this phenomenon and reported the need for such instrument.

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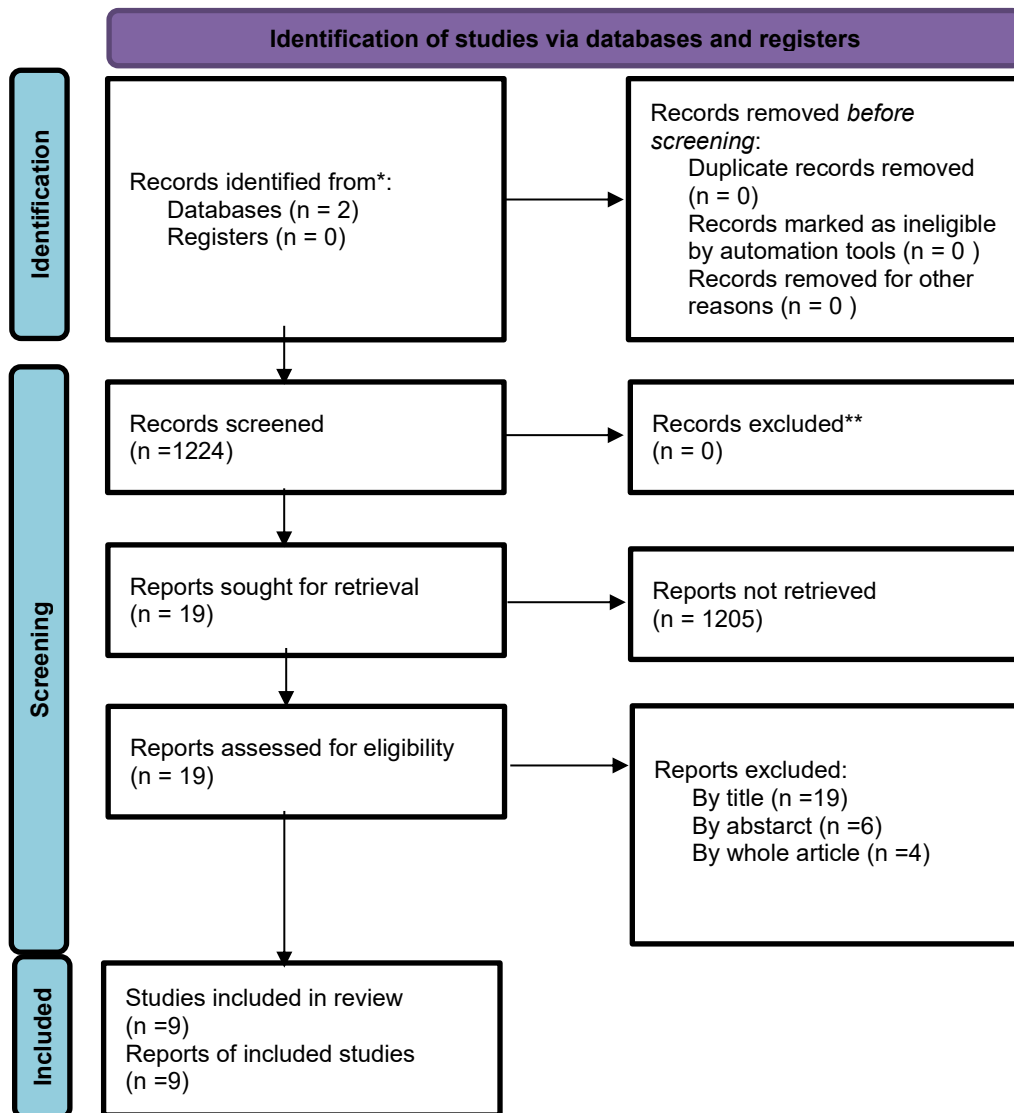
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Appendices

Appendix 1. Database search protocol

Database	Search terms	Hits and date
PubMed/Medline	(self-neglec* OR self neglect*) AND (old people* OR old person* OR senior* OR aged* OR elder* OR "Aged"[Mesh] OR "Aged, 80 and over"[Mesh]) AND (evaluat* OR assess OR rate* OR instrument)	1224 5.7.2023
CINAHL	("self-neglec*" OR "self neglect*" OR MH "Self Neglect") AND ("old people*" OR "old person*" OR senior* OR aged* OR elder* OR MH "Aged+" OR MH "Aged, 80 and Over") AND (evaluat* OR assess OR rate* OR instrument)	241 5.7.2023

Appendix 2. Prisma flow chart 2020



(Page et al. 2020)

Appendix 3. Evaluation form for translation of SN-37

Turun yliopisto
 Hoitotieteen laitos
 20014 Turun yliopisto
 Self-neglect assessment scale SN-37 käännös
 Asiantuntijapaneeli
 _____.02.2024

Osallistujan taustatiedot:

Ammatti: sairaanhoitaja lähihoitaja

Työkokemus kotihoidossa vuosina: _____

Ohje:

Arvioi jokaisen väittämän suomenkielinen käännös asteikolla 1-4

1 = ei oleellinen/selkeä

2 = ei pysty arvioimaan oleellisuutta/selkeyttä

3 = olennainen, mutta tarvitsee vähän muutoksia

4 = erittäin oleellinen/selkeä ja ytimekäs

Oleellisuus= kuinka hyvin mielestäsi väittämä mittaa iäkkään itsensä laiminlyöntiä

Selkeys= kuinka selkeä/hyvä/ymmärrettävä käännös mielestäsi on

Jos arvioit väittämän asteikolla 1-3, kirjaathan kommenttikenttään perustelun arvioinnille

Ympäristö (12 väittämää)

Arviointi

1. Yksilö ei kykene saamaan ja/tai valmistamaan ateriaita	Oleellisuus	Selkeys
	1 2 3 4	1 2 3 4
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

2. Yksilö elää asunnossa/talossa, missä ei ole kaikkea varustusta/mahdollisuutta täyttämään yksilön fyysisiä tarpeita (esim pyörätuoli, käsituet kylpyhuoneessa tai eteisessä tai rampeja, huono valaistus, polttoaineen vähyys)	Oleellisuus	Selkeys
	1 2 3 4	1 2 3 4
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

3. Yksilöllä on kasaama esineitä, jotka ovat turvallisuusriskejä

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

4. Yksilö asuu talossa/asunnossa, mikä on erittäin kylmä

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

5. Yksilö asuu talossa/asunnossa, mikä ei ole turvallinen (esimerkiksi tulipalovaaroja, reduced)

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

6. Yksilö hamstraa eläimiä

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

7. Yksilö syö pilaantunutta ruokaa

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

8. Yksilöllä ei ole pääsyä kylpytiloihin

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

9. Yksilöllä ei ole varoja/rahaa maksaa laskuja ('hyötytavaroita utilities, rakennus- tai kodinkorjauksia jne)

Oleellisuus	Selkeys
1 2 3 4	1 2 3 4
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Kommentti: _____

- | | | |
|--|---|---|
| 10. Yksilö asuu talossa/asunnossa, missä on näyttöä tuholaisista | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 11. Yksilö ei maksa laskuja, vaikka yksilöllä on riittävät tulot ne maksaa | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 12. Yksilö asuu talossa/asunnossa, missä laitteet eivät toimi (putket, jääkaappi, valaistus, puhelin jne) | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

Sosiaalinen kanssakäyminen (7 väittämää)

- | | | |
|--|---|---|
| 13. Yksilö on sosiaalisesti erakoitunut ja omaa rajoittuneet sosiaaliset suhteet naapureihin | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 14. Yksilö ei ole puhunut kenenkään kanssa kuluneen viikon aikana | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

15. Yksilö asuu yksin

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

16. Yksilöltä puuttuu sosiaalisia suhteita (perhe, ystävät, naapurit), joiden puoleen kääntyä hätätilanteessa

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

17. Yksilö välttelee ystäviä, perheitä, uskonnollisia ja sosiaalisia tapahtumia

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

18. Yksilön yhteydenpito perheenjäsenten, ystävien ja naapurin kanssa on vähemmän toistuvaa kuin olisi välttämätöntä hänen tarpeisiinsa

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

19. Yksilöllä ei ole ketään, joka voisi tarjota hänelle tarvitsemaansa tukea

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

Tunteet ja käytös (8 väittämää)

20. Yksilö ilmaisee pelkoa jokapäiväisessä tilanteissa

Oleellisuus

1 2 3 4

Selkeys

1 2 3 4

Kommentti: _____

- | | | |
|--|---|---|
| 21. Yksilö osoittaa pelkoa tiettyihin ihmisiin, jotka ovat häntä lähellä | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 22. Yksilö osoittaa aggressiivista, vihamielistä käytöstä | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 23. Yksilö luottaa ihmisiin, jotka ovat todistaneet että heihin ei voi luottaa | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 24. Yksilön käytös todennäköisesti aiheuttaa fyysistä vahinkoa toisille | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 25. Yksilö ei ole poistunut talostaan/asunnostaan yli kuukauteen | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 26. Yksilö näyttäytyy surullisena (esimerkiksi onneton, synkkä, valittava) | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 27. Yksilö käyttää liikaa huumeita/alkoholia | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

Terveyden välttely (6 väittämää)

- | | | |
|--|---|---|
| 28. Yksilöllä on hoitamattomia / silmälläpitämättömiä jalkavaivoja | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 29. Yksilö ei piittaa/jättää huomiotta sairauden merkit ja oireet | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|---|---|---|
| 30. Yksilö ei vie läpi ennaltaehkäisevää tai diagnosia testejä, jotka ovat yhteydessä terveydentilaan | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|--|---|---|
| 31. Yksilö ei noudata lääkärin määräämiä ohjeita reseptilääkkeissä (ali/ylilääkitystä, tai määrämättömien reseptilääkkeiden käyttöä) | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

- | | | |
|-------------------------------|---|---|
| 32. Yksilö hamstraa lääkkeitä | Oleellisuus | Selkeys |
| | 1 2 3 4 | 1 2 3 4 |
| | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |

Kommentti: _____

33. Yksilöllä esiintyy suunnittelematonta viimeaikaista painon pudotusta

Oleellisuus				Selkeys			
1	2	3	4	1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentti: _____

Itsemääräminen (4 väittämää)

34. Yksilö ei tee yhteistyötä tai halua ottaa vastaan apua

Oleellisuus				Selkeys			
1	2	3	4	1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentti: _____

35. Yksilöllä on itsensä laiminlyömiseen viittaavaa käytöstä aikaisemmin elämässään

Oleellisuus				Selkeys			
1	2	3	4	1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentti: _____

36. Yksilö on vastahakoinen ottamaan vastaan apua päivittäiseen hoitoonsa

Oleellisuus				Selkeys			
1	2	3	4	1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentti: _____

37. Yksilö laiminlyö henkilökohtaisen hygieniansa (likaiset vaatteet, paha haju, epäsiisti olemus)

Oleellisuus				Selkeys			
1	2	3	4	1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentti: _____

Appendix4. Information letter about the research

TIEDOTE TUTKIMUKSESTA – IÄKKÄÄN HENKILÖN ITSENSÄ HUOLENPIDON HAASTEET – ARVIOINTITYÖKALUN ASIAANTUNTIJAPANEELI

Teitä pyydetään mukaan tutkimukseen asiantuntijapaneeliin, jossa selvitetään iäkkään itsestä huolenpitoa ja sen haasteita. Olemme arvioineet, että soveltuisitte mukaan tutkimukseen, koska olette terveydenhuollon ammattilainen, työskentelette kotihoidossa, Teillä on käytännön kokemusta tutkittavasta aihealueesta ja äidinkielenne on suomi. Tämä tiedote kuvaa tutkimusta ja Teidän mahdollista osuuttanne siinä. Lukekaa rauhassa tämä tiedote. Jos Teillä on kysyttävää, voitte olla yhteydessä tutkimushenkilökuntaan (yhteystiedot löytyvät asiakirjan lopusta). Jos päätätte osallistua tutkimukseen, Teitä pyydetään allekirjoittamaan tietoinen suostumus asiantuntijapaneeliin osallistumisesta.

Tämän tutkimuksen toteuttavat Turun yliopiston hoitotieteen ja tulevaisuuden teknologioiden laitos. Tutkimuksen rekisterinpitäjä on Turun yliopiston hoitotieteen laitos, joka vastaa tutkimuksen yhteydessä tapahtuvan tietojen käsittelyn lainmukaisuudesta.

Tutkimuksen tausta ja tarkoitus

Tämä tutkimuksen tarkoituksena on arvioida olemassa olevia itsehoidon laiminlyönnin arviointityökaluja, arvioida psykometriikaltaan luotettavin instrumentti iäkkään itsehoidon laiminlyönnin arviointiin ja kääntää se alkuperäiskieleltä suomen kielelle. Tämän lisäksi käännettyä instrumenttia on tarkoitus arvioida asiantuntijapaneelissa. Asiantuntijoiden on tarkoitus arvioida instrumentin väittämien relevanssia ja selkeyttä.

Tämän tutkimuksen tavoitteena on auttaa tunnistamaan iäkkään väestön itsensä laiminlyönti ja siten parantaa iäkkäiden terveyttä ja hyvinvointia, sekä auttaa havaitsemaan ja ratkaisemaan ongelma mahdollisimman varhaisessa vaiheessa.

Osallistumisen vapaaehtoisuus

Tähän tutkimukseen osallistuminen on vapaaehtoista. Voitte kieltäytyä osallistumasta tutkimukseen tai peruuttaa suostumuksenne syytä ilmoittamatta, milloin tahansa tutkimuksen aikana.

Tutkimuksen toteutus

Asiantuntijapaneelissa asiantuntijoiden on tarkoitus arvioida käännöksen oleellisuutta ilmiön kohden ja selkeyttä. Tutkimukseen pyydetään mukaan asiantuntijoita, jotka ovat peruskoulutukseltaan joko lähi- tai sairaanhoitajia ja jotka työskentelevät kotihoidossa. Paneelissa on aluksi tarkoitus selvittää iäkkään itsensä laiminlyönnin käsitettä, minkä jälkeen asiantuntijat arvioivat arviointityökalun väittämien oleellisuutta ja selkeyttä arviointiasteikolla 1-4 ja tarvittaessa avoimella kommentilla. Arvioinnin jälkeen paneeliin osallistujat käyvät tutkijan johdolla ohjattua keskustelua väittämistä. Asiantuntijapaneeliin varataan aikaa kaksi (2) tuntia, ajankohta ilmoitetaan osallistujille myöhemmin.

Tutkimuksen mahdolliset hyödyt

Tutkimuksen tuloksia tullaan hyödyntämään kehitettäessä iäkkäiden yksilöiden itsehoitoa ja välinettä, jonka avulla voidaan tunnistaa mahdollista avun tarvetta itsehoitoon liittyen. Osallistumisestanne tulee olemaan hyötyä myös pidemmällä aikavälillä arviointivälineen kehittämisessä. Lyhyellä aikavälillä hyödytte tutkimuksesta oman ammattitiedon lisäämisellä.

Tietojen luottamuksellisuus ja tietosuojaja

Tutkimusaineistoa käsittelevät vain aineiston kerääjät, tutkija ja tutkimuksen ohjaajat professori Riitta Suhonen ja dosentti Minna Stolt Turun yliopistolta. Aineistoa ei luovuteta tutkimusryhmän ulkopuolisille henkilöille, ja tunnistetietoja ei kerätä. Aineistoa käytetään tässä kuvattuun tieteelliseen tutkimukseen.

Antamanne tiedot käsitellään ehdottoman luottamuksellisina. Aineisto käsitellään ja säilytetään tietoturvallisesti Turun yliopiston hoitotieteen laitoksella. Tutkijat käsittelevät aineistoa tietokoneelle tallennettuina tiedostoina, joista ei ilmene vastaajien henkilötietoja. Tutkimusaineisto säilytetään Turun yliopiston hoitotieteen laitoksella. Tietojenne säilytysaikaa sääntelee lainsäädäntö sekä hyvä eettinen tutkimustapa.

Tutkimuksen oikeusperusta

Tätä tutkimusta varten on tullut saada puoltava lausunto eettiseltä toimikunnalta.

Hankkeen tuotokset

Tulokset tullaan julkaisemaan Turun yliopisto lääketieteellisen tiedekunnan hoitotieteen laitoksen pro gradu -tutkielmana ja tieteellisenä artikkelina.

Lisätietoja

Jos Teillä on kysyttävää tutkimuksesta tai haluatte osallistua tutkimukseen, voitte olla yhteydessä tutkimushenkilökuntaan.

Yhteystiedot:

Laura Hämäläinen TtM-opiskelija Hoitotieteen laitos 20014 Turun yliopisto Puh: 040 934 9479
Laura.hamalainen@utu.fi

Riitta
Professori, Turun yliopisto Hoitotieteen laitos
20014 Turun yliopisto Puh: 050 435 0662 riitta.suhonen@utu.fi

Appendix5. Informed consent

SUOSTUMUS TUTKIMUKSEEN

IÄKKÄÄN HENKILÖN ITSENSÄ LAIMINLYÖNTI – ARVIOINTIKALUN VALIDOINTI, ASIAANTUNTIJAPANEELI

Minua _____ on pyydetty osallistumaan yllämainittuun tieteellisen tutkimuksen asiantuntijapaneeliin, jonka tarkoituksena on arvioida tutkimuksessa käännettyä itsehoidon laiminlyönnin arviointityökalun väittämien oleellisuutta ja selkeyttä. Olen lukenut ja ymmärtänyt saamani kirjallisen tutkimustiedotteen. Tiedotteesta olen saanut riittävän selvityksen tutkimuksesta ja sen yhteydessä suoritettavasta tietojen keräämisestä, käsittelystä ja luovuttamisesta. Tiedotteen sisältö on kerrottu minulle myös suullisesti, minulla on ollut mahdollisuus esittää kysymyksiä ja olen saanut riittävän vastauksen kaikkiin tutkimusta koskeviin kysymyksiini.

Tiedot antoi _____ __ / __ / 20 __. Minulla on ollut riittävästi aikaa harkita osallistumistani tutkimukseen. Olen saanut riittävät tiedot oikeuksistani, tutkimuksen tarkoituksesta ja sen toteutuksesta sekä tutkimuksen hyödyistä ja riskeistä. Minua ei ole painostettu eikä houkuteltu osallistumaan tutkimukseen.

Ymmärrän, että osallistumiseni on vapaaehtoista. Olen selvillä siitä, että voin peruuttaa tämän suostumukseni koska tahansa syytä ilmoittamatta eikä peruutukseni vaikuta kohteluuni tai saamaani hoitoon millään tavalla. Tiedän, että tietojani käsitellään luottamuksellisesti eikä niitä luovuteta sivullisille.

Allekirjoituksellani vahvistan osallistumiseni tähän tutkimukseen ja suostun vapaaehtoisesti asiantuntijapaneeliin.

Asiantuntijan nimi Asiantuntijan syntymäaika Asiantuntijan osoite

Päivämäärä Allekirjoitus

Suostumus vastaanotettu

Tutkijan nimi

Päivämäärä

Allekirjoitus